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Georgia L. Carragher
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**Life after diagnosis: The social experience of adolescents
diagnosed with attention-deficit/hyperactivity disorder and
how they manage their lives.**

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**A thesis submitted in fulfillment of the requirements of the award of Doctor of
Philosophy**

Submitted: 1st December 2003

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Hope is the thing with feathers

That perches in the soul,

And never sings the tune without the words,

And never stops at all,

And sweetest in the gale is heard; ...

Emily Dickson 1830-1886 (*Complete Poems*, 1924)

Abstract

Attention-Deficit/Hyperactivity Disorder is the most frequently diagnosed developmental disorder in school-age children in Western Australia today. It concerns and frustrates the children and adolescents who are diagnosed with the disorder, their parents, teachers and the general community. In spite of the plethora of research associated with AD/HD, dissension abounds in the community, literature and the media over its diagnosis and the best treatment and response to the disorder. Notwithstanding the body of research very little is known about adolescents' experiences, opinions, needs and problems associated with the disorder as research and treatment regimes are currently determined by adults. The research on which this dissertation is based uses the grounded theory method for data collection and analysis to gain insights into the social experience of a small group of Western Australian adolescents diagnosed with AD/HD receiving stimulant medication treatment. In doing so this research extends current research becoming the first grounded theory study with adolescents with AD/HD in Western Australia. The issues examined in my research focus on the adolescents perception of the impact of their diagnosis and stimulant medication use on their social environment and how they manage their lives. A substantive theory emerged that explains the social problem faced by these adolescents and the complex basic social-psychological process by which they endeavour to resolve the difficulties that they face so as to be able to manage their lives. The discussion includes extracts from the data and literature to demonstrate how the substantive theory Reaching for the Light emerged from my research and the social theories that determine how adolescents view their world. The theory Reaching for the Light is composed of four levels of process; *seeking solutions*, *transforming*, *scaffolding* and *potentialising* and two near core categories (*balancing* and *fortressing*) interrelating as they pass through stages. Working with this small group of adolescents in order to present their worldview of the impact of AD/HD and stimulant medication, rather than that of adults, was both challenging and fascinating particularly taking into account the different cultural perceptions that exist between adults and adolescents.

For those with AD/HD social condemnation relating to their diagnosis and stimulant medication treatment is the general rule so that the adolescents fear labeling and marginalisation. Being aware of the participants' fears I, therefore, took care to ensure their anonymity at all times. My research presents a new picture of how adolescents with AD/HD are able to manage their lives and shows the importance of involving adolescents in decisions about themselves and how positive, patient and constructive social interaction from the adults in their lives can assist them. It emerged from the data that where support and social experience are negative low self-esteem increased the probability of risk-taking behaviour associated with stimulant medication and attempted suicide. This dissertation that focuses on the social experience of a small group of adolescents with AD/HD is oriented around the belief that with effective support these adolescents are able to manage their lives.

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;
- (ii) contain any material previously published or written by another person except where due reference;

is made in the text; or
- (iii) contain any defamatory material.

Note: This thesis has been formulated in accord with modified American Psychological Association (2001) publication guidelines fifth edition in association with Edith Cowan University Doctoral and Masters by Research Handbook (2003).

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CHAPTER ONE

Introduction

Attention-Deficit/Hyperactivity Disorder (AD/HD) is the most frequently diagnosed developmental disorder in school-age children in Western Australia today. It is a puzzling and frustrating problem for the children and adolescents who are diagnosed with the disorder, their parents, teachers and the general community. In spite of the plethora of research associated with AD/HD, dissension abounds in the community, literature and the media over its diagnosis and the best treatment and response to the disorder. Notwithstanding this body of research related to AD/HD very little is known about adolescents' experiences, opinions, needs and problems associated with the disorder. In effect adults, that is doctors, teachers and parents, conventionally determine current AD/HD research and treatment regimes. The opinion of the adolescents themselves is rarely, if ever, sought.

In western society, adolescence is regarded as a time of transition when the adolescent seeks to shed the yoke of parental control and take responsibility for themselves. The adolescent diagnosed with AD/HD seeks equitability and autonomy in the same way as their peers without AD/HD. Yet, parents of adolescents with AD/HD are reluctant to 'hand over the reins', fearing that the adolescent's lack of planning and organisational skills coupled with their tendency for impulsive behaviour will prove detrimental to them.

This research presents the story of how a group of adolescents diagnosed with AD/HD manage their lives in Perth, Western Australia. Adopting a qualitative grounded theory approach, this thesis examines the impact of the diagnosis and the

usage of stimulant medication associated with AD/HD from the adolescents' perspective, in order to determine how adolescents cope with the social, cultural and personal stigma attached to the disorder. In doing so, I show how this group of adolescents seek to manage their lives and the processes they employ in order to reach their aims and goals. I also reveal how they cope with the problems and conflicts that they encounter during this process.

As a discourse that locates the researcher and the research within the qualitative grounded theory tradition the language of this thesis tends toward the introspective, revealing at times the very thoughts of the researcher. My research acknowledges the subjective role of the researcher in the research process. Where this research reflects my own concepts and involvements in the research the language I use is in the first person.

The purpose of chapter one is to clarify why this research was thought to be necessary. Chapter one first documents the problem statement relating to AD/HD and the period of life referred to as adolescence; second, this chapter presents the need for the research and its aims followed by a brief discussion on the research approach used. It concludes with an outline of the subsequent chapters and the limitations of this study.

Problem Statement

Attention-Deficit/Hyperactivity Disorder

The disorder AD/HD is a persistent pattern of inattention and/or hyperactive-impulsivity more frequently displayed and more severe than typically observed in other individuals (Barkley, 1998; T. Brown, 2002; Hazell, 2002; Hutchins, 2002). The current diagnostic criteria used to identify AD/HD are defined in The American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition – Text Revision (DSM-IV-TR™) (American Psychiatric Association, 2000).

For a condition to be regarded as a valid medical or psychiatric disorder its bona fides must be established (Barkley, Cook, et al., 2002). According to Barkley, Cook, et al. (2002), the veracity of a condition/disorder may be established if that

condition/disorder meets the criteria for harmful dysfunction. To meet these criteria there must be unequivocal scientific evidence of a failure in or deficit of a mechanism that appears in all other humans and that this deficiency leads to harm to the individual. According to Barkley, Cook, et al. (2002, p. 90), "the central psychological deficits in those with AD/HD have now been linked through numerous studies using various scientific methods to several specific brain regions". It is believed that these areas of the brain regulate social, cognitive and behavioural mechanisms for individuals (Barkley, 1997a; Cooper & Shea, 1998; Pennington & Ozonoff, 1996; Tannock, 1998b). In the opinion of Barkley (Barkley, 1997a, 2000; Barkley, Koplowitz, Anderson, & McMurray, 1997; T. Brown, 2002; Hutchins, 2002), those with AD/HD are deficient in impaired behavioural inhibition that leads to secondary deficiencies in executive function. Executive functions are those that contribute to self-regulation and are: working memory and sense of time; self-regulation of emotional and motivational states; the internalisation of speech and reconstitution; and the formation of novel, complex behavioural sequences. Deficits in executive function and impaired behavioural inhibition are linked to and have a bearing on educational, family and social outcomes for children and adolescents with AD/HD. The result of these deficits is that these children and adolescents are at significant risk of under-achievement and under productivity in school, at home and socially compared to their peers without AD/HD. As Jensen and Abikoff (2000, p. 641) assert, "many times a child or adolescent may present with such severe ADHD¹ symptoms that he or she is in danger of failing in school or of being suspended or expelled". In later life 50% of those with AD/HD are likely to under-achieve in employment (Barkley, 1997c; Barkley, 1998; Rubenstein & Brown, 1981).

As the Consensus Statement by Barkley, Cook, et al., (2002, p. 90) affirmed, "there is no doubt that ADHD leads to impairments in major life activities, including social relations, education, family functioning, occupational functioning, self-sufficiency and adherence to social rules, norms, and laws".

Many of those with AD/HD will experience peer relationship problems, with a few being friendless (Jensen & Abikoff, 2000; Rotenberg & Hymel, 1999). Parkhurst

¹ Throughout my research attention-deficit/hyperactivity disorder is abbreviated AD/HD. Where a quotation from a reference uses the abbreviation ADHD without the slash it will be presented as originally written by its author.

and Hopmeyer (1999) suggested, that where a child's biological deficits led to low self-esteem they may have indirectly contributed to their loneliness; this was particularly so when peer rejection and social rejection occurred due to unacceptable behaviours. Low self-esteem has been shown to be a significant and constant problem for those with AD/HD (Frankel, Cantwell, Myatt, & Feinberg, 1999; Hinshaw, 2002; Rucklidge & Kaplan, 2000). A health-related quality of life study in children and adolescents with mental disorders (including AD/HD) undertaken by Sawyer, Whaites, Rey, Hazell, Graetz and Baghurst (2002) reported that children with mental disorders experience significantly worse health-related quality of life than those with no disorder, or a physical disorder. Sawyer, Whaites et al. (2002) also noted that the problems experienced by and with these children and adolescents with a mental health problem interfered significantly with their daily lives and those of their parents and families. Yet, according to Slomkowski, Klein and Mannuzza (1995), despite research identifying higher than average levels of depressive or anxiety symptoms in those with AD/HD, few objective self-report studies have been undertaken. Rucklidge and Kaplan (2000) came to the same conclusion in their research with females. This lack of research specifically directed at inquiring into the perceptions of those with AD/HD, particularly adolescents, is of particular concern given Bussing's (2000) opinion that self-esteem levels directly correlate with the presence or absence of depressive or anxiety symptoms. Robin (1998) had previously also reached the same conclusion when he stated that the tremendous negative impact of low self-esteem and sadness resulting from life failure experiences caused by AD/HD should not be underestimated.

The problems associated with AD/HD are not confined to the diagnosed individual. Families of adolescents with AD/HD have been found to experience greater stress and conflict than is normally associated with adolescence (Hazell, 2002; Robin, 1998). Research has also demonstrated that mothers of children with AD/HD were more likely to experience elevated levels of depressive symptoms than mothers whose adolescents' were not AD/HD (Johnston, Murray, Hinshaw, Pelham, & Hoza, 2002). In Johnson et al.'s opinion, mothers of adolescents with AD/HD who experienced symptoms of depression may not respond appropriately and sensitively to their child's behaviour. This lack of appropriate responsiveness by the mother may

instigate or aggravate the child's problematic behaviour. Edwards, Barkley, Laneri, Fletcher and Metevia (2001) had also expressed this view a year earlier.

For the most part, AD/HD and its attendant treatment regimes is the subject of much contentious discussion in both the literature and the media. The media particularly castigates parents for not controlling their children and adolescents. As Barkley, Cook, et al. (2002) and Levy, Hay, McStephen, Wood, and Waldman (1997) assert, however, despite social perceptions to the contrary, underlying psychological deficits that comprise AD/HD itself are not solely or primarily the result of social environment, that is poor parenting. Rather, as twin studies demonstrated, family environment made no significant separate contribution to the traits of the disorder AD/HD.

The adolescent, as is documented, confronts many new tasks and challenges from those of the younger child. The adolescent also tends to more risk-taking behaviours, either because of their sense of invulnerability, or to impress and improve their standing with their peers and to raise their level of self-esteem. In the opinion of Rabiner (2000), an individual's self-esteem depended to a large extent on the success those individuals experienced with their peers. Risk-taking behaviour was seen, therefore, as a way of attracting peer recognition (Jaffe, 1998). For the adolescent with AD/HD these tasks and challenges were fraught with difficulties brought about by the traits of their disorder (such as inhibition and inattention) and the public perception of the disorder (Barkley, 1998). Risk-taking behaviour, an integral part of adolescence, was exacerbated in those with AD/HD particularly when their lack of inhibition was taken into account (Barkley, 1998; 2001b; Robin, 1998). As Barkley (1998; 2001b) and others testified, research has demonstrated that adolescents with AD/HD tended to exhibit a higher degree of risk-taking behaviour than their peers without AD/HD. They were at increased risk of motor vehicle incidents (e.g., speeding tickets, accidents, license suspensions and revocations), early experimentation with sex and concomitant increased incidences of teenage pregnancy and sexually transmitted disease. For example, a longitudinal study in New Zealand (Woodward, Fergusson, & Horwood, 2000) studied the driving outcomes for a group of adolescents. The conclusions from Woodward, Fergusson and Horwood's study were that, even after adjustment for confounding factors such as driving experience, gender and conduct problems, the

adolescents with AD/HD were more at risk of accident, injury and possibly also risky driving behaviour than those without (Woodward et al., 2000).

The benefits of stimulant medication for those with AD/HD have been demonstrated by improved outcomes such as raised levels of concentration and attention. Adolescents who were appropriately treated with stimulant medication were less distracted and impulsive and experienced increased organisational abilities in 70% to 90% of cases (Cantwell, 1996; Conners, 2002; Greenhill, Halperin, & Abikoff, 1999; National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999; Prince, 2002; Prosser & Reid, 1999). At the same time, both children and adolescents with AD/HD who were prescribed stimulant medication reported higher self-esteem levels than those with AD/HD who were not medicated (Frankel, Cantwell, Myatt, & Feinberg, 1999). According to Jensen and Abikoff (2000) and Abramowitz, O'Leary and Dulcan (1992), consensual opinion supported the view that the state-of-the-art treatment for AD/HD should involve both behaviour therapy and pharmacology appropriate to the needs of the individual. The MTA Cooperative Group Study (1999) concluded, however, that carefully crafted medication management was superior to behavioural treatment for core AD/HD symptoms. The MTA Cooperative Group also found that combined behavioural and medication management did not furnish significantly greater benefits than medication alone for core symptoms of AD/HD, but may lead to modest benefits for non-AD/HD symptoms and functioning outcomes.

Although research has indicated that stimulant medication is one of the most effective treatments for adolescents with AD/HD, for its efficacy to be maintained throughout their formal education they must continue to take it (Conners, 2002; Faigel, Sznajderman, Tishby, Turel, & Pinus, 1995; Prince, 2002). As a study by Garland (1998) reported, the benefits from medication only continue while it is being ingested. Adolescents with AD/HD have been shown, however, to have low compliance rates for treatment (including stimulant medication use) (Greenhill, Halperin & Abikoff, 1999). Despite stimulant medication being demonstrated to be one of the most effective treatments, it is not uncommon for adolescents to believe that they do not need medication and to refuse to take it. Adolescents' have cited behavioural changes and peer perceptions associated with stimulant medication as reasons for discontinuing usage over extended periods (Bowen, Fenton, & Rappaport,

1991; Landau & Moore, 1991; Polis, 2001). Yet, as Bowen, Fenton and Rappaport (1991) amongst others contended the general tendency has been for researchers to ignore the relationship between treatment and the views of those being treated, in this case the adolescents with AD/HD. Furthermore, as Jensen and Abikoff (2000) and Baxley and Turner (1978, p. 172) have argued, young people are rarely, if ever, consulted about their treatment, yet it is they who are "expected to ingest the medication and become active participants in their own treatment". This is despite research by Tracey and Gleeson (1998) and Sleishman (2000) which identified the need for the involvement of adolescents in the decision making process with regard to strategies and treatment. According to Sleishman, negotiation can assist adults and adolescents to co-construct better solutions to difficulties occurring between them. Presently, the lack of medication compliance in adolescents with AD/HD leads to difficulties for parents and clinicians and may lead them to question whether ongoing benefits from medication are outweighed by the problems associated with persuading an adolescent to take it (Jensen & Abikoff, 2000).

Friction between adults and adolescents is not uncommon. According to Jensen and Abikoff (2000), Faigel et al. (1995), and Baxley and Turner (1978) in an earlier opinion, an adolescent's desire for autonomy in conjunction with their natural rejection of adult regimes tends to present problems. When adolescents also have AD/HD these problems are increased. For the parent of an adolescent with AD/HD their adolescent's opposition to adult authority is of greater significance because, according to Barkley (1998; 2001b) and Robin (1998), the adolescent with AD/HD has a lack of planning and organisational skills and tends to demonstrate impulsive behaviour. Moreover, parents of these adolescents are reluctant to allow them to take responsibility for themselves. The reasons cited for maintaining parental control are the well-documented lack of medication and treatment compliance and problems such as an increased risk for negative driving outcomes and increases in sexual transmitted disease and teenage pregnancy (documented by Barkley, 2001b; Rabiner, 2003; Riddell, 1991; Robin, 1998; Woodward et al., 2000).

Despite the considerable body of research associated with AD/HD treatment strategies and stimulant medication, research specifically aimed at investigating the impact of the disorder and stimulant medication usage on the lives of adolescent males and females with AD/HD, from their own experience, has been minimal. This view is

based on an evaluation of current AD/HD research. Studies directed at ascertaining the opinions of those diagnosed with AD/HD have usually been undertaken with boys. For the most part these studies have been conducted with children aged between six and 12 years, rather than adolescents, and taken the form of either self-report questionnaires completed by the children or double-blind placebo-controlled medication trials involving self-assessments.

In the opinion of Tracey and Gleeson (1998), very little was known about adolescents' own opinions, experiences, needs and problems related to AD/HD and stimulant medication usage. This view was supported by Rabiner (2003) in his AD/HD research update. B.H. Smith, Pelham, Gnagy, Molina, and Evans (2000) also upheld this opinion in their research on adolescents using stimulant medication. Those studies seeking adolescent perspectives have largely been quantitative rather than qualitative by design, with evaluation of AD/HD in adolescence and its outcomes gauged according to paper and pencil measures or double-blind placebo medication trials thus consequently limiting the scope of the research. According to Barkley (1981; 1998) and Robin (1998), these studies were of questionable reliability, reflecting a certain bias, since assessment questionnaires were adult-directed instruments. At the same time, child self-report questionnaires researching children's own assessments of their behaviour that could have provided valuable information were still regarded with suspicion and mistrust (Langsford, 1999; Rohrbeck, Azar, & Wagner, 1991).

The decision making process that determines if an adolescent has AD/HD and whether that adolescent requires treatment, including stimulant medication is currently predominantly brought about through social intercourse between the parents, medical practitioners and at times teachers. In effect, current AD/HD research and treatment regimes are for the most part conventionally determined by the adults responsible for the well-being of the child, such as doctors, teachers and parents. It is their views, in conjunction with social perspectives that are the guiding principles which determine current conceptualisations of AD/HD and stimulant medication usage and the pathway for treatment regimes and management strategies.

Studies by Prosser (1998; 2000) and Sawyer, Whaites et al. (2002) in Australia and Cooper and Shea (1998) in the United Kingdom have begun to address this dearth of research into adolescents with AD/HD. Nevertheless, research has barely begun to

address the appropriate needs and important issues relating to the experience of adolescents who have been diagnosed with AD/HD and how they manage their lives. To date, there would appear to be little or no recourse to the real world comprehension of their experiences and opinions, or needs and problems, including their educational, emotional and support requirements. Presently, the majority of AD/HD research is verificational research, theory testing, with an over reliance on pre-existing adult-directed research instruments. Nor, to any degree, has research sought the opinions of adolescents with AD/HD to elicit the impact of their diagnosis and stimulant medication use on their home, school and social life. Neither has research sought to develop a theory on how adolescents with AD/HD (both male and female) are able to manage their lives. If self-esteem and social and educational outcomes for adolescents with AD/HD are to be improved then there is a need to address these limitations and establish a greater understanding of AD/HD in adolescence, from the unique perspective of the adolescent.

The Adolescent Stage of Life

The dominant academic theories, which form the basis for current social understanding of adolescents and that period of life referred to as adolescence, stem from sociology, anthropology and psychology. The theories which underlie these disciplines, such as socialisation, sickness and illness, medicalisation, deviance and stigma, while being of long standing, still provide a framework through which adolescents and the stage of life referred to as adolescence are viewed by contemporary society. Where an individual does not conform to social perceptions and expectations these theories determine society's view of that individual. Western society constructs sickness and disease in terms of the medical model of health. Within this discourse individuals are defined by their deficits, which are seen as a deviance from socially accepted norms to be controlled by the medical profession. Individuals who experience complex problems such as depression or alcoholism are seen to be not coping and are treated medically rather than society addressing the social issues that may be responsible for their problems (Grbich, 1996). Physical and mental health is regarded as mandatory if individuals are to participate fully in society (Grbich, 1996). Correspondingly, a lessening in public acceptance for self-limiting conditions that affect social and educational outcomes for the individual (Searight & McLaren, 1998) has led to an increased classification of diseases worthy of medical

attention (Barsky & Borus, 1995). This medical ideology that abstracts 'the body' from the social and historical context and lived experience has been used, in recent years, to address physiologically deviating disorders such as AD/HD (Barsky & Borus, 1995). This model has its foundations in several paradigmatic theories including structural functionalism, symbolic interactionism incorporating labelling theory, phenomenological sociology and the conflict-theory (Gerhardt, 1989). It is these paradigms which are responsible for sustaining current ideology concerning the theoretical foundations of medical sociology and contributing to what are considered to be important ideas on sociological theoretical concepts (Davis, Watson, & Cunningham-Burley, 2001; Gerhardt, 1989).

As with AD/HD research, quantitative research has dominated adolescent developmental research: presenting adolescents as objects not subjects (Woodhead & Faulkner, 2001). As yet, the voices of children and adolescents have not often been heard even though it is they who have produced their own unique cultures (A. B. Smith, Taylor, & Gollop, 2000; Woodhead & Faulkner, 2001). Qualitative research that illustrated the experience of children and adolescents tended to be regarded with scepticism, due in part to the public perception, based on sociological theories, that the views of children and adolescents were not valid (Woodhead & Faulkner, 2001). Theories such as socialisation still appear to dominate cultural perspectives of childhood and adolescence. This is in spite of the endeavours of scholars such as Corsaro (1997) Mayall (1994) and A.B. Smith, Taylor, et al. (2000, p. ix) who propounded the paradigm of the sociology of childhood which "views children as subjects rather than objects and as active participants in, rather than the passive recipients of, research, policy and provision of services". As Corsaro (1997, p. 5) argued, "we tend to think only of childhood solely as a period when children are prepared for entry into society. But children are already part of society at their birth as childhood is part and parcel of society". In Corsaro's view for children and adolescents childhood² is a phase that changes on the journey to adulthood as it moves forward. Society, however, perceives that childhood is an enduring stage, changing only with socially initiated historical and conceptual contexts (Corsaro, 1997).

² In my research the term childhood refers to the period of time prior to adulthood and subsequent to infancy. Childhood, therefore, encompasses both children and adolescents.

A considerable body of research has discounted the old adage that described adolescence as a time of storm and stress (Garbarino, 1993; Jaffe, 1998). According to Jaffe, stereotyping of adolescents as obnoxious, rebellious and out of control was not accurate, realistic or fair, because it implied that all adolescents were the same. According to Jaffe, neither research nor careful everyday observations confirmed these stereotypical representations. For the most part the majority of adolescents got on well with their parents (Garbarino, 1993; Jaffe, 1998). Adults should also be aware that it was adult perceptions of young people which guide parenting behaviours, school policy and curriculum and social attitudes. Jaffe argued, therefore, that if adults only perceived adolescents as dangerous and out of control, then they felt compelled to limit the adolescents' freedom and increase adult control over them. Jaffe also raised the suggestion that media sensationalisation of antisocial behaviour in adolescence may have been responsible for the public stereotyping of all adolescents on the basis of a non-representative sample of poorly behaved young people. Adolescence, as with any other stage of life, was a time where stress and conflict may occur (Garbarino, 1993; Jaffe, 1998). In Garbarino's (1993) view, however, where behaviours give rise to concern they usually indicated genuinely serious problems.

Adolescents with AD/HD experience persistent difficulties with attention, and(or) hyperactive impulsivity that impinge on their family and their social and educational outcomes. These problems are exacerbated by contentious public debate associated with stimulant medication, which research has identified as one of the most effective treatments for AD/HD. Nonetheless, both AD/HD and adolescent research in general rarely canvas the adolescent's viewpoint with regard to the problems in their lives and treatment for their disorder but is directed by adult opinion.

Need for the Research

As the problem statement indicates, sociological, anthropological and psychological research into adolescents and AD/HD regimes raise very complex issues. Many eminent academics and clinicians have studied these issues at length. Some sections of society, such as researchers, medical practitioners and the media, still portray AD/HD as a myth lacking validity. Moreover, research into adolescents and the adolescent stage of life remains fixed by long standing theories such as socialisation, sickness and health, deviance and stigma theory and medicalisation.

With the exception of a limited number of studies, such as those of Prosser (1998), Cooper and Shea (1998) and Sawyer, Rey et al. (2002), the experience of adolescents with AD/HD has, for the most part, been discounted or even ignored. According to A.B. Smith, Taylor, et al. (2000), this experience was mirrored with research relating to the adolescent stage of life. In general, therefore, the experience of adolescents with or without AD/HD has been that of an adult directed life in which the voice of the adolescent was rarely given credence or was even disregarded (Adams, 2000; Alderson, 1995; Jenks, 1992, 2001; Oakley, 1994; Woodhead & Faulkner, 2001). Recommendations have been made in the literature to increase the application of qualitative research relating to adolescents and the adolescent stage of life as well as for those with AD/HD (Hazell, 1997a, 2002; Prosser, 1998, 2000; A.B. Smith, Taylor, et al., 2000; Woodhead & Faulkner, 2001). The aim of my research is to expand the focus of AD/HD adolescent research. In doing so this study presents the voices and experiences of a small group of adolescents diagnosed with AD/HD and depicts how the contemporary views of AD/HD are socially constructed.

Aim of the Research

The substantive area of enquiry relates to how a small group of male and female adolescents in Western Australia (WA) who have been diagnosed with AD/HD and who receive stimulant medication as treatment, manage their lives in light of their social experience. In this qualitative study the grounded theory methodology will be used to form a theory about this. An attempt will be made to explain the social problems encountered by these adolescents, the processes by which they manage their lives and the ways in which they try to resolve the difficulties they meet in their lives.

Orientation of the Research and the Research Question

The grounded theory method was chosen for my research because Glaser and Strauss's (1967) grounded theory approach, with its roots in Blumer's (1969) symbolic interactionism, enable a researcher to discover theory about a phenomenon in a substantive and specific area of empirical enquiry. The grounded theory approach is consistent with the orientation of my research question, which seeks to discover the

world through the eyes of the participants and then the basic social processes or structures that organise their world. The central research question is:

What is the experience of adolescents in WA diagnosed with AD/HD with regards to their diagnosis and the use of medication in the context of their home, school and social environment; in what ways do they manage their lives?

The grounded theory method as the systematic generation of theory from data acquired through a rigorous research method is not findings, but rather is an integrated set of concepts and hypotheses (Glaser, 1998). In a substantive grounded theory the integrated set of concepts account for much of the behaviour seen in a substantive area and embody the every day reality of this substantive area. A substantive theory is born in and helps to explain the real world (Hutchinson, 1988). The constant comparative verificational approach of grounded theory in which data are constantly coded and analysed ensures that a substantive theory has fit, work and relevance to the specific area under study, with a high level of conceptual density and theoretical completeness. As Glaser (1998, p. 4) asserted, "grounded theory is the discovery of what is there and emerges. It is NOT invented".

Thesis Outline

In research that tests existing theory the researcher carefully reviews literature to ascertain how the hypothesis to be tested has previously been studied to assist in research design decisions. Grounded theory on the other hand is based on a discovery model of theory development. Following in the grounded theory tradition (Chenitz & Swanson, 1986) chapter two is not, therefore, intended to be a full literature review but will discuss the background literature relating to AD/HD and stimulant medication and literature associated with the period of life referred to as adolescence in order to document existing knowledge and information. It is consistent with grounded theory research that further literature may be identified as relevant during data analysis. This literature may not, however, become apparent during the initial literature search but only emerge as the data is collected and analysed.

Inherent within the grounded theory method is the need for the researcher to be cautious about allowing literature to direct thinking that categorises incoming data into learned concepts and relationships, therefore, unconsciously closing off new information that may appear in the analysis (Glaser, 1998). It was Glaser's contention that "it is hard enough to generate one's concepts without the added burden of contending with the rich derailments provided by "a" literature in the form of manifest assumptions of what ought to be found in the data"(p. 69). In order to prevent the "preconceiving, grabbing effects of the literature search" (Glaser, 1998, p. 73), literature should be used as an on-going source of data to be "constantly corrected, put into perspective and proportioned in relevance by the constant comparative method" (Glaser, 1998, p. 73). The study of literature in grounded theory analysis is, therefore, an on-going process in which literature is woven into the study to provide a broader picture of the area under review and allow the study to transcend current thinking.

Chapter three then seeks to locate the reader within the framework of this qualitative research which is underpinned by symbolic interactionism set within the interpretative paradigm. Chapter three also outlines the influence of prior experience and the researcher as an instrument of inquiry and the theoretical constructs that informed the overarching paradigm for this research. Ethical considerations and the criteria for evaluating qualitative research delineated by Piantanida and Garman (1999) that may be used to judge research are also discussed.

Chapter four commences by presenting the central research question. Chapter four then details the scope of the study, the research method (design and procedures) and how the data collection and analysis were approached using the grounded theory method. A study set in this way allows for inductive theory building to occur. The works of Glasser (1978; 1992; 1998; 2001), Glaser and Strauss (1967) and Strauss and Corbin (1990; 1994; 1998) were employed to direct the use of the grounded theory method in my research. Glaser's (1998) criteria for evaluating a grounded theory study are discussed in chapter four along with measures relating to the verification of issues of generalisability and reproducibility and the need for validity.

Chapter five discusses the basic social problem experienced by the adolescent participants that was discovered during data analysis. It also details the way in which the core category and core process emerged from the data. Chapter five culminates by presenting an overview of the substantive theory that emerged from the data analysis.

This theory, as a basic social-psychological process, signifies how adolescents with AD/HD appear to manage their lives. It is presented in the form of a final storyline selective code note. The typologies of support that emerged as areas that influenced how well each participant was able to manage their life are presented as a theoretical memo. Subsequent chapters expand upon and discuss this theory and the emergent typologies of support in greater detail.

Chapter six discusses the way in which the basic social-psychological process that adolescents with AD/HD employ to manage their lives was discovered and the primary concerns that emerged from the data and the impact of these primary concerns on how the adolescents manage their lives. In chapter six each category of process and the various properties of each of the categories as they were identified in the data are described. Extracts from participants' transcribed interviews are included to demonstrate the development of the categories and their properties as they were identified.

Chapter seven discusses the typologies of support that emerged from the category *scaffolding*³ and how these supporting typologies interact with the substantive theory. Typologies may be used to depict the way in which an area is investigated and conceptualised (Glaser, 1978). In my research typologies are conceptualised as the four different levels of support available to the adolescent participants. Chapter seven delineates the differing typologies of support in the context of the how and why and the particular form of support that each adolescent with AD/HD is presented with and the bearing the support has on the way in which they manage their lives.

The last chapter, chapter eight, draws this research to its end and presents the overall outcomes and the primary concerns that were discovered. Chapter eight also makes suggestions for future research and re-examines the two sets of criteria, identified in chapters three and four, that I employed to evaluate my research. The criteria are those of Piantanida and Garman (1999) discussed in chapter three for judging qualitative research and Glaser (1998) and Strauss and Corbin's (1990; 1998) criteria for reviewing grounded theory presented in chapter four.

³ Where a word in the text denotes a concept such as a category, property or dimension discovered in the data analysis it is italicised.

A Word about Cope and Manage in the context of my Research

In my research the terms used to describe action-interaction strategies include cope with and manage. Coping, according to Frydenberg (1997), is the way in which an individual, through their thoughts, feelings and actions, responds to problematic situations they encounter in their day-to-day world; it is regarded as a stress alleviating action. Whereas, manage focuses on the capacity of each individual to deal effectively and holistically with the social processes that determine their lives (Frydenberg, 1997). The Macquarie Dictionary (Delbridge et al., 2001, p. 649) defines 'manage' as "succeeding in one's aims especially against heavy odds". Cope is defined thus: "to deal effectively or contend successfully with a person or task" (Delbridge et al., 2001, p. 246). As the data will confirm, in the eyes of the research participants the definitions presented here are consistent with their views.

Great care was taken in determining the choice of the word 'manage' to describe the way in which the adolescent participants articulated how they directed their lives. Several other words were tested for my research including coping, arrange and conduct. Manage, however, provided the clearest, most appropriate definition to account for the actions/interactions and behaviours that form the basic social-psychological process. Arrange and conduct were discarded as the data indicated that the adolescents considered that they managed their lives and coped with problems by adopting specific strategies to handle individual issues. Arrange and conduct, therefore, did not lend themselves to my research in that they were not terminology that was consistent with the adolescent way of thinking.

Limitations of the Research

My research is grounded in the experience of a small group of adolescents in WA who were diagnosed with AD/HD by a paediatrician and who receive stimulant medication to treat their disorder. I acknowledge that the overall outcomes and the primary concerns that are presented do not provide a universal, generalised or representative picture of the experiences of all adolescents with AD/HD. Rather the adolescents who participated in this research have lived their experiences at a specific point in time in their lives.

In excess of 50 adolescents with AD/HD and their parents were contacted but only 10 of the adolescents approached agreed to participate in my research. Whether this reluctance on the part of adolescents to talk was due to their poor self-esteem, or the natural reluctance of adolescents to converse with an adult I can only guess. I hope that future research may redress this limitation with a greater number of voices of adolescents and children with AD/HD being presented.

Nevertheless, the constant comparative method of theory discovery, that is grounded theory analysis, has enabled the core concepts (themes and variables) discovered in my research to be elevated to a level of theoretical abstraction sufficient to generate a substantive theory. This substantive theory is capable of being tested in future studies using different settings.

CHAPTER TWO

Background

Structure of Chapter

Chapter two presents itself in two ways: first, it outlines the way in which the period known as adolescence was engaged with and understood throughout the research. Second, it will present the current research and literature related to AD/HD in adolescence and the use of stimulant medication. The following format is used to present this information. Initially, chapter two presents the background literature associated with adolescent development from the perspective of adults and the theories that are associated with adolescence and adolescent development. Chapter two then defines adolescence as a stage of life and, thereafter, presents literature outlining the adolescent point of view relating to the adolescent stage of life. This first section is then followed by literature associated with AD/HD that is presented in the following order: an introduction; the history; overview of the diagnosis including WA diagnostic criteria; heredity, genetics, gender and self esteem in AD/HD; comorbidity and AD/HD; executive functions, stimulant medication and medication compliance in adolescence and multi-modal treatment. This section on AD/HD culminates with the risks associated with the disorder and social perceptions. Chapter two concludes with a summary of the literature related to the adolescent stage of life and that of AD/HD.

The decision to present chapter two as a background chapter was consistent with the grounded theory method utilised for my research (Chenitz & Swanson, 1986) underpinned by Blumer's (1969) symbolic interactionist tradition. As Irurita (1990, p.

33) observed "unlike research directed at theory testing or verification of a pre-existing theory, the initial literature review in grounded theory studies is primarily aimed at identifying the scope, range, intent and type of research that has been undertaken in the area".

Through this format the reader will become aware of the prevailing knowledge and understanding relating to AD/HD and stimulant medication and be able to position it in the context of 'adolescence', as a stage in the life of an individual.

The symbolic interactionist approach of Henry Blumer (1969) had its foundations in the following three principles:

1. How human beings act towards things is based on the meaning or understanding they assign to them;
2. That they comprehend things by continuously assigning symbolic meaning to them; and
3. The way in which human beings apportion meaning to things is an outcome of social interaction in human society.

Grounded theory is a discovery model of theory development that aims "to account for and explain phenomena in the social world" (Chenitz & Swanson, 1986, p. 44). Blumer's (1969) principles of symbolic interactionism empower grounded theory analysis to comprehend the realities of the world not only from the perspective of others, but from within the realm of individual consciousness and the subjective beliefs assigned by an individual to the social interaction with others.

To the grounded theorist all literature is "approached as data ... to be reviewed in the context of the ... analytic concepts and relationships to concepts identified in the literature" (Chenitz & Swanson, 1986, p. 44). Literature, therefore, is a source of data through which to discover more about the area under research and the conditions under which phenomena occur. From the rudimentary beginnings of the research until its end, literature plays its part. Moreover, as analysis proceeds and concepts and categories develop, so literature appropriate to each particular analytic stage and its components is reviewed. As a result, the rationale stimulating the literature search changes during the duration of the research as new information and data are sorted. By the end of the research, the researcher "will have a thorough knowledge of the

literature and will be able to place the theory in context with existing theories and work on the subject" (Chenitz & Swanson, 1986, p. 45).

The Adolescent Stage of Life

Introduction

The specific rationale motivating this research was to identify the current perceptions of adolescents with AD/HD relating to the impact of social environment, diagnosis of AD/HD and utilisation of stimulant medication on the ways in which they manage their lives. To develop a story of how adolescents with AD/HD manage their lives it was first necessary to comprehend the social theories that determine current social understanding relating to the adolescent stage of life.

The first section of chapter two introduces the dominant theories that form the basis for the current social understanding of the period of life referred to as adolescence. The framework that determines how adolescents with AD/HD understand and construct a picture of their world is derived from the social perspectives that direct social beliefs relating to the adolescent stage of life. Durkheim's social functionalist theory - that we are all members of societies which exert social constraint over our actions - still carries currency according to Woodhead and Faulkner (2001), Mayall (1994) and Giddens (1993). This understanding is based on the knowledge that the theory of social imagination, written by C. Wright Mills in the 1950s, remains the benchmark for sociological study in Australia today. His sociology of the imagination is considered as *a propos* today as it was when it was written.

According to Gitlin, C. Wright Mills was "the most inspiring sociologist of the second half of the twentieth century" (Gitlin, 2000, p. 229). As Gitlin stated:

He (Mills) hammered home again and again the notion that people lived lives that were not only bounded by social circumstance but deeply shaped by social forces not of their own making, and that this irreducible fact had two consequences: it lent most human life a tragic aspect with a social root, and also created the potential - if only people

saw a way forward – of improving life in a big way by concerted action. (Gitlin, 2000, p. 230)

It was C. Wright Mills' opinion that "sociological imagination enables us to grasp history and biography and the relations between the two within society" (Gitlin, 2000, p. 6). For, "we have come to know that every individual lives, from one generation to the next, in some society: that he lives out a biography, and that he lives it out in some historical sequence" (2000, p. 6). According to Gitlin, C. Wright Mills' viewpoint stemmed from the perspectives of classical social analysts such as Emile Durkheim, Auguste Comte, Karl Manneheim and Karl Marx. It was the views of these scholars that were perpetuated in contemporary studies of the individual and society as the following paragraphs demonstrate.

Adolescent Research: The Adult Perspective

My research has sought to discover how adolescents with AD/HD manage their lives and their views on their diagnosis and stimulant medication. Presently, however, adolescence is seen and understood not from the point of view of the adolescents themselves but as adult directed concepts. The following discussion is directed at explaining how and why the adult position relating to the adolescent period of life still constrains research and knowledge and why the new theories, such as sociology of childhood are only now slowly finding their place in research.

Studies by scholars such as Mayall (1994), Oakley (1994) and A.B. Smith, Taylor, et al. (2000), have argued that it is important for adults to realise that children and adolescents have a significant contribution to make in helping adults to understand the nature of childhood. Davie (1993), in a paper to the psychological community, also put forward a similar notion in which he suggested that it was time to "Listen to the child: a time to change" (p. 225). Davie argued that now was the time for those responsible for child care issues (i.e., psychologists, educators, health services and the law) to pay attention to the child's perspective. Woodhead and Faulkner (2001) when discussing Davie's thoughts, argued that this appeal may, at first have appeared incongruous, given the role of the psychologist in the community, but it was not inappropriate. Academic research in the areas of children and adolescents in the opinion of Woodhead and Faulkner (2001) has been founded on generations of

painstaking work aimed at eliciting children's sense of self and understanding of their world. Although research in the domains of children and adolescence has sought to elicit the child or adolescent perspective of their world, research instruments and research data have tended to be constructed or interpreted from the researcher's perspective rather than reflecting the child or adolescent point of view. Moreover, the body of knowledge from which child development theories evolved was "constructed by adults for other adults to use in order to make sense of, regulate and promote children's lives and learning" (Woodhead & Faulkner, p. 11).

In the opinion of Oakley (1994) and Mayall (1994, p. 114), "adult behaviours towards children are conditioned by the understanding that they are best regarded as beings in process". It was Oakley's (1994) position that theories related to childhood and adolescence tended to remain centred on what children and adolescents are not, rather than what they are. Childhood is understood as a social construct, "a social status delineated by boundaries incorporated within the social structure and manifested through certain typical forms of conduct, all of which are essentially related to a particular cultural setting" (Jenks, 1982, p. 12; and Jenks, 1992). How adolescents and children are differentiated in their world is dependent upon their social status - social identity (Jenks, 1982, 1992). As Jenks (1982, p. 12) argued, "the social propensity to routinize and naturalize childhood ... serves to conceal its import behind the cloak of the mundane". According to Jenks (2001), in 20 years nothing has changed despite the many studies stressing the need for research knowledge to be directed by the young person's perspective rather than that of the adult. Rather, "analytic inversions and transformations have been utilised to render the mundane and taken-for-granted problematic" (p. 62). As Alderson (1995) explained:

...most research directly on children is devoted to measuring them, using the model of animal research to measure their growth, disease or behaviour. Such research can bring great benefits to children's health and education. Yet it is largely impersonal. If children's views are collected, this is usually to atomise and process them through the grid of adult designed research. (p. 40)

The following comment from Woodhead and Faulkner (2001) presented the argument most succinctly:

To put it crudely, while 'listening carefully' is considered basic good practice in psychological research, alongside 'observing systematically' and 'recording accurately', these research values are for the most part a means to an end, not an end in themselves. Research projects are framed in terms of any number of academic, policy or professional agendas. The research process is generally controlled by researchers not children (especially in the case of structured laboratory procedures). The research product is 'data' interpreted in terms of adult discourses about children's development... (p. 11-12)

Engaging with Woodhead and Faulkner's (2001) point regarding structured laboratory procedures my research also argues that, as quantitative research dominates both adolescent developmental research and AD/HD research relating to adolescents, adolescents either with or without AD/HD will continue to be presented as objects not subjects. This perspective is supported in two ways first, by Woodhead and Faulkner's observation that "the principles of experimental design, measurement and statistical analysis remain central to undergraduate research methods courses" (2001, p. 30). Second, through A.B. Smith, Taylor, et al.'s (2000, p. 2) observation that child and adolescent experience or performance is repeatedly measured through "highly structured assessments, such as questionnaires, observations test and structured interviews". Their comments, which support research by Hetherington and Clingempeel (1992), imply that quantitative research techniques learned by undergraduates endure in postgraduate research work. My argument is not that quantitative research is not relevant and important in child and adolescent research, but that currently, there is an imbalance in the research methods undertaken with children and adolescents. Presently, because of the lack of qualitative research young people are rarely encouraged or permitted to articulate their experience of their lives.

Until theory specific to children and adolescents which focuses on their social environment from the perspective of that child or adolescent is able to direct social thinking, the emphasis remains not on what children and adolescents are but what they will become "in their status as would be adults" (Oakley, 1994, p. 23). For example, Coleman and Hendry (1990, p. 2) perceived adolescence as a transitional process in which "the individual passes from one state – childhood – to another – maturity – and that the issues and problems faced by individuals during this period are predominantly the result of the transitional process". Ritchie and Koller (1964) had much earlier referred to adolescence in the same vein when they stated that adolescence was the 'port of entry' to adulthood. Adams (2000), on the other hand, referred to adolescence as the 'twilight zone'. A.B. Smith, Taylor, et al. contended that these perceptions implied that adolescents were pre adult or lesser adults who were "progressing towards adulthood through the process of socialisation in families and schools" (2000, p. 2). Adams argued that current perceptions were reinforced by long standing sociological theories that constrain contemporary research.

The following quotation from Valsiner (1997) explains how the rationale behind the previous arguments could eventuate. He argued that:

The establishment of psychology as a social institution within a society leads to a state of affairs where it cannot transcend its own sociocultural context, because success in that context amounts to a lessening of the immediate social value. The discipline is caught within a debilitating paradox: *In order to arrive at basic knowledge, it would have to diminish its immediate social usefulness (i.e., potential for application). However, as long as it tries to build up knowledge on the basis of applied concerns (which are relevant for its success in any society). It cannot advance its basic knowledge.* The ethos of psychology's image as a socially helpful science makes it helpless in its own epistemological advancement. (p. 311)

Discussion on the Adult Perspective of Adolescent Research

This background review of literature relating to the adolescent stage of life asserts that the dominant academic social theories that are applied to research into

adolescence remain the same today as prevailed throughout the latter part of the 20th century. This view is supported by the opinions of A.B. Smith, Taylor, et al., (2000), Valsiner (1997), Woodhead and Faulkner (2001) and C. Wright Mills (Gitlin, 2000). This is in spite of the growing number of monographs, edited volumes and journal articles addressing both theoretical and empirical issues, as well as the evolution of new theories relating to childhood and adolescence, such as the sociology of childhood and sociocultural perspectives (Corsaro, 1997; A.B. Smith, Taylor, et al., 2000).

During the period my research was conducted emergent theories, such as the sociology of childhood, aimed at changing the focus for research about adolescents did not appear to be having any significant impact on the how the adolescent participants in my research viewed the structure of their lives. Currently, adolescents are regarded as dependent beings to be socialised, rather than identifying them as independent actors that are basic units of society.

This background chapter acknowledges, however, that research exists that recognises children and adolescents' views and "attends to the meanings that children construct as participants in their own development" (A.B. Smith, Taylor, et al., 2000, p. 2). This research by A.B. Smith, Taylor, et al. and others corresponds with the beliefs that directed my research. These beliefs are that children and adolescents have a right to have their voices heard and for their opinions to influence how their lives are ordered. I recognise, however, that changing the position of children and adolescents in the social and cultural sciences requires a re-examination of the conceptual frameworks that influence children's' and adolescents' representation.

As Oakley (1994) argued research has tended to produce general descriptions of children and childhood and analyses relationships between variables, which then produced grand overarching generalisations. These descriptions, however, have provided little insight into the everyday environment of children and childhood. The experiences of children and young people remain that of a world where adult decision-making and socialisation predominate (Adams, 2000; Alderson, 1995; Jenks, 1992; 2001; Oakley, 1994; A.B. Smith, Taylor, et al., 2000; Woodhead & Faulkner, 2001). Chapter two and subsequent chapters will, therefore, discuss the data in light of those theories that continue (aside from them being of long standing) to provide a framework through which adolescents and the stage referred to as adolescence are viewed by contemporary society. For, despite my research being positioned to present

the perspective of a group of adolescents with AD/HD, it would appear that an adolescents' perspective is governed by the way in which their world is constructed. It is not the intention of my research to discount new theories such as the sociology of childhood, but to point out that they are not sufficiently established in the area currently under review to be incorporated fully into this chapter.

Current Theories of Adolescence and their Implications for this Research

According to Adams (2000), the theories that dominate adolescent research in the main stem from the disciplines of sociology, psychology along with developmental psychology and anthropology. These disciplines and their attendant theories will now be addressed.

Sociological Perspective

The sociological perspective contextualises human behaviour in relation to influencing factors such as neighbourhood, socioeconomic levels, demographics, family (including parental upbringing) and available schooling (Adams, 2000). Sociological perspectives, as they relate to "individual and life courses, are culturally constructed" (Hammer, 1998, p. 83). In Hammer's opinion, the course of life in contemporary society is determined by "institutionalized sequences of events, positions and roles which shape the individual's progression in time and space" (p. 83). According to Hammer, the way in which an individual behaves is determined by the socio-cultural conditioning of a given group. Processes that inform cultural groups in western society include socialisation, sickness and mental illness theories, normality, deviance and labelling theories and the medical model of health (medicalisation). The pathway their life will follow is determined by cultural perceptions and definitions of "needs, competencies, tasks and behaviors thought to be appropriate for individuals belonging to a given age group" (Hammer, 1998, p. 83).

Socialisation is the overarching "process whereby individuals learn to become social beings through interaction with other people and societal structures" (Edgar, Earle, & Fopp, 1993, p. 274). Socialisation assumes that the fixed roles, values and expectations of a socialising group determine conventions of behaviour. It is this socialisation process that thus allows individuals to participate on an equal footing in

society as socially aware and socially competent individuals (Hunt, 1978; Riddell, 1991). The basic premise inherent in the socialisation process is to furnish an individual with the wherewithal to cope with the everyday world; have conformity of character and be good and well mannered (Elkin & Handel, 1884).

While socialisation of children in Australia is primarily the responsibility of the family, other social entities such as education, religion, economy, government and leisure and the mass media are also accorded the role of socialising agencies (Denzin & Lincoln, 2000). It should be noted, however, that the mass media differs in its socialising influence due to its lack of interaction with individuals.

In reality, each of the socialising entities in Australia today, despite appearing to present different sociological viewpoints, demonstrate some shared ideas, beliefs, assumptions, values, expectations and appropriate patterns of behaviour. It is these shared expectations that form the culture of a group (Craig, 1996). The primary function for the socialising agencies remains one of ensuring that children acknowledge and comprehend social expectations of normatively appropriate behaviour, not as a prescriptive list of behaviours but as an abstract model offering general guidance. For the individual is not responding directionally to social conditioning but is actively adapting to the circumstances in which they find themselves (Woods, 1992). According to Cheek, Shoebridge, Willis and Zadoroznj (1996), bodies such as teachers, nurses and doctors act as agents of social control to assist the family and help to maintain the degree of conformity with roles and norms that can be reasonably expected of an individual. These bodies also define the amount of deviance that society will tolerate in order to maintain equilibrium.

Wallace and Wolf (1991) contend that social equilibrium or homeostasis is maintained through shared values and generally accepted standards of social action and interaction. Homeostasis is considered essential for society to preserve social order. Social definitions of behaviours and the socially approved consequences were thus tied to society's definition of values, norms, expectations and conventions (Tuchman, 1996). When, however, an individual or group of individuals deviates from these socially defined processes society perceives it will lead to the disintegration of the social system that maintains homeostatic social order for that society (Gerhardt, 1989).

The theories of normality and deviance, in conjunction with stigma theory, labelling theory, the medical and social models of health and sickness and mental illness theories, serve as indicators for how the social environment is constructed of technical and social content. These constructs prescribe and proscribe certain action(s), where all social action(s) is seen as exchange (Pfuhl & Henry, 1993; Pilgrim & Rogers, 1990; Whitehead, 1992). Laws, rules, regulations and moral values define the norms that direct these theories that proscribe normally accepted behaviours. In these terms, normality assumes that frequently occurring behaviours in a population are normal and those that occur infrequently are abnormal - deviant.

According to Becker (1973; 1964; 1985) and also Gove (1975), labels served many purposes; they illuminate cultural and professional values and define and intrinsically communicate functions and cognition. For example, "not staying in one's seat in the classroom becomes a problem because of the cultural preference in most schools for silent and sedentary work" (Prosser, Reid, Shute, & Atkinson, 2002, p. 73).

Bowers (1998) developed Gove's suggestions further by asserting that it is the social audience, rather than the individual actor, who determined whether an action or behaviour is deviant. Once labelled, the individual assumes the status and identity ascribed to them thus leading to them being stigmatised by society as deviant. Those who are regarded as intrinsically different or deviant - such as those with AD/HD - become marginalised to safeguard society's overall general health and equilibrium (Pilgrim & Rogers, 1990; Pfuhl & Henry, 1993). Those, whose behaviour is given this label of different, such as those with AD/HD, are further reduced in the mind of the observer to one who is tainted: a spoiled identity (Goffman, 1968, 1974).

The social perception of deviance emerged from sickness and mental health theories. These theories assert that health is defined as the capacity to fulfil roles that make up society and embody the understanding of the dual notion of illness whereby health is perceived as normal and illness as negative or deviant requiring control (Gerhardt, 1989).

In the opinion of Davis, Watson, and Cunningham-Burley (2001), the models of normality, deviance, stigma and the medical and social models of health and

labelling may be better understood if they are looked at in the context of two specific notions: those of Piaget and the medical model of health (medicalisation).

In the Piagetian notion of the naturally developing child, emphasis is placed on the child's ability to actively make sense of the world by selecting, interpreting and conceptualising what they hear and feel in the world around them (Giddens, 1993).

The medical model of health (medicalisation) measures bodies and minds against physical and cognitive norms defined by society. Medical knowledge is both authoritative and authoritarian, according to Cheek et al., (1996) and developed from legitimate knowledge stemming from the times and culture. With the medical model any condition that cannot be proved scientifically is greeted with scepticism (Cheek et al., 1996). Those who do not conform to universal standardised developmental targets are pathologised (Davis et al., 2001). For example, AD/HD "has become a common, yet ambiguous, mental disorder treated primarily from the medical paradigm, because ADHD is responsive to stimulant medication" (Searight & McLaren, 1998, p. 490). For those diagnosed as having a disorder such as AD/HD, the medicalisation of the disorder obligates them to return to a state of good health (normality) and to behave according to the conventions of their society (Petersen & Waddell, 1998). If these individuals, however, choose not to conform to societal expectations or the medical profession does not cure them, society perceives them and labels them further as secondary deviants. Once this process emerges, the individual must then reconstruct their notions of self in terms of their attitudes, feelings and social expectations in order to be accepted by society (Gerhardt, 1989). Gove (1975) in his discussion of deviance and labelling had previously posited this notion of secondary deviation.

Cheek et al. (1996) argued that more and more life experiences are defined in terms of health and illness and given medical meaning. This medicalisation of areas of human experience, such as childhood developmental behaviours and ageing, accords the medical profession the right to diagnose and treat what might have previously been regarded as life stages (Cheek et al., 1996). In the opinion of Barsky and Borus (1995), however, it has been the somatisation (relating to the body as distinct from the mind) of symptoms that has been responsible for the progressive medicalisation of disorders. Furthermore, Barsky and Borus contended that the medicalisation of disorders such as AD/HD is determined by social and cultural forces, influenced by public intolerance to behaviours regarded as unacceptable. Their views accord with those of Pfuhl and

Henry (1993), Rutter, Giller and Hagell (1998) and Whitehead (1992), who argued that the entrenched meaning of 'normality' derives from social norms that are the shared expectations of how people ought to behave or act in certain circumstances. Society obliges an individual to conform to role expectations set by others as a continuous validation of symbolic meanings through interpersonal exchange (Gerhardt, 1989). Those who do not conform to social expectations are devalued in the eyes of society, disempowered, marginalised and stigmatised (Cheek et al., 1996).

Summary of Sociological Perspective

Sociological research provides an insight into how context influences human behaviour and determines the shared social expectations of behaviour. Sociology identifies the effects of family, neighbourhood and schooling on the individual and provides the context for the socialisation of the individual. How an individual is viewed by society depends on that individual's ability to conform to social expectations, norms and values. The models of normality, deviance, stigma and the medical and social models of health and labelling are socially constructed. Medicalisation of behaviours considered by society to be non-conformist, such as childhood developmental behaviours and ageing, afford society the right, through the medical profession, to diagnose and treat what society regards as problematic.

Psychological Perspective

The psychological (including psychosocial and cognitive development) research approach into adolescent development has its foundations in theories such as those of Freud (psychosexual development), Erickson (identity model), Piaget (stage development approach), Kolberg (cognitive developmental approach to adolescent morality) and Vygotsky (personal construct theory). Granville Stanley Hall (1844-1924), however, has been recognised as the father of adolescent psychology (Berzonsky, 2000). Hall regarded adolescence as a time of 'rebirth' when the adolescent develops social responsibility and becomes aware of the rights and welfare of others (Berzonsky, 2000). According to Berzonsky, it was Hall who coined the phrase 'storm and stress' to describe the period when adolescents struggle between self-interest and social good as they seek to become civilised members of society. Muuss (1996) contended, however, that many of these early theorists were male-

centric, neglecting or ignoring females, a trend that Muuss argued only recently changed.

One aspect of adolescent development that appears to cross all theoretical boundaries is gender. Gender and gender differences, particularly as they relate to growth and maturity and their effects on human behaviour, play a role in the understanding of human life. Studies by Adams (2000), Davis et al. (2001), Kalat (1990) and Muuss (1996) have indicated that in contemporary psychosocial and anthropological research, gender is one of the major influences on family relationships and determined socialisation trends in families. The way in which boys and girls are treated provides the basis for measuring not only the different relationships between males and females, adolescents and adults, but also the differences that exist across cultures. Muuss, for example, suggested that the distinction between girlhood and womanhood is less noticeable than boyhood and manhood. According to Muuss, girls were more likely to be involved overall with their mothers but also other females in their community, whereas boys, in his opinion, were likely to be more closely involved with their peers than their fathers or other adult males.

My research has involved studying the experiences of adolescents with AD/HD related to family, friends and school. Acknowledging, therefore, some of the gender related issues and their affects, particularly on family relationships, is appropriate at this juncture.

Summary of the Psychological Perspective

Adams (2000) delineates several theories including that of Hall's that have dominated discussions on psychosocial development in adolescence during the 20th century. In Adams' view each of these theories has addressed differing aspects of the adolescent stage of life, with no one theory capturing adolescent development across all contexts. In theories related to adolescent psychosocial development, gender differences and the way in which the different genders are socialised, is one determinant of how male and female relationships develop (Muuss, 1996). Muuss also argues that socialisation based on gender has a bearing on the way in which gender was viewed across cultures.

Anthropological Perspective

On the one hand, sociological and in particular socialisation theories seek to define the culture of a society or group. On the other hand, the anthropological perspective bases its distinctions upon cultural mores and differences that exist between and within cultures and which influence behaviour (Adams, 2000). Margaret Mead (1901-1978), in her anthropological dissertation on Samoan youth revealed that adolescent behaviour differed from culture to culture (1928). Mead's research and other anthropological studies that followed, led to the development of the theory of cultural relativism. This theory suggested that the way adolescents act and cope with problems they encountered was directed by the culture of the world in which they lived (Berzonsky, 2000). Adolescence, from the anthropologically constructed perspective, is viewed as a transitional period during which the adolescent acquires and constructs knowledge. This knowledge derives from and is interpreted in the context of the society that surrounded the adolescent (Caputo, 1995). According to Muuss (1996), each society differs in the way they recognise adolescence as a unique developmental phase in the life cycle. In the opinion of Muuss, for the most part, all societies have clearly recognisable social 'markers' that delineate and define the transition from childhood to adolescence and sometimes even adulthood.

According to Barnes (1996), in a qualitative grounded theory study the culture(s) of participants may differ significantly from that of the researcher. Grounded theory data analysis, therefore, requires that special attention be given to methodological issues. Understanding cultural difference was a specific need of my research where I, as the researcher, am a mature adult, having a different cultural perspective from that of the participants who are adolescents. Individual cultures develop their own guidelines that direct conduct in specific situations. My being aware of cultural differences was crucial, therefore, for the data collection and analysis processes. Cultural awareness is of particular relevance as the guidelines promoted by each culture are recognised as 'norms' according to Haralambos and Holborn (1991). The culture of a society determines how members of that society think and feel, as well as the behaviours acceptable to that society (Haralambos & Holborn, 1991). Culture, according to Barth (2002), may be seen as knowledge. According to Weiner (2002), Barth's broad definition of knowledge not only encompasses practice, culture or structure, but also voices the mutual influence each of these features has upon each

other. Knowledge is what a person employs to interpret and the define they way in which they act in the world. Knowledge embodies skills, feelings (attitudes) and information. Knowledge refers to the way in which we understand things and use our experience to grasp reality:

We all live lives full of raw and unexpected events, and we can grasp them only if we can interpret them – cast them in terms of our knowledge or, best anticipate them by means of our knowledge so that we can focus on them and meet them to some degree prepared and with appropriate measure. (Barth, 2002, p. 1)

Socialisation is the process responsible for individuals learning the culture of their society. In western society the socialisation process is directed, for the most part, by significant agencies such as family and school. Peer groups, however, are also responsible for determining culture (Haralambos & Holborn, 1991). Style of dress is a good example of a 'norm' that differs from group to group and situation to situation. Language and musical taste too may differ from group to group but nonetheless define a group. For example, adolescents tend to have distinct preferences with regards discourse style, dress and music. In the early 1990s according to Danesi (1994), rap, house and hard rock were the music focuses with the fashion focus tending to follow that of the music. Currently, adolescent preferences in music tend to the eclectic, with the sounds of the 1960s, 70s and 80s still finding followers. Metal Storm one of the newer heavy metal music groups, with their 'dark', satanic music that focuses on the occult, has I am informed, a big male following at present. According to Jaffe (1998, p. 298) "action films and heavy metal music have been especially appealing to male teenagers, many of whom are high in sensation seeking". For the most part, however, adolescents seek and select media materials according to their particular personalities and needs. The adolescent's choice of media materials tends to reflect important aspects of themselves and their views of the world (Arnett, Larson, & Offer, 1995).

Being aware of what was important to the adolescent participants and where necessary asking them to explain various aspects of their culture to me allowed me to develop a better relationship with them. It was my view that if I was to fully understand the social experiences of the adolescent participants in my research then it was necessary for me to understand the language they used in conversations with me

and also why they regarded certain aspects of their lives important. I have also found the way in which they perceive things, such as dress, or understand issues relating to the drug culture, to be not only of interest but often intriguing. I was of the belief that it was critical for me to comprehend culturally specific nuances in adolescent language, if I was to be able to understand and develop concepts from data during the data analysis process. For example, a word that appears in both adolescent and adult culture but with different connotations is the word cool. To the adult cool implies to the opposite of hot, in a physical sense. To the adolescent cool simultaneously encapsulates and displays how the teenager thinks and behaves, 'like uh, it's *cool* to be *cool*' (Danesi, 1994; Pountain & Robins, 2002). It is acknowledged, however, that some adults will attempt to annex adolescent definitions associated with the word cool in an effort to ingratiate themselves with a specific group of young individuals. Whether adolescents appreciate this attempt by adults to show they 'understand' them is debatable and not an issue I will enter into at this juncture.

Summary of the Anthropological Perspective

Anthropological research has over the years sought to understand the way in which a culture is directed and directs the lives of those within its precincts. Anthropological theories relating to the adolescent stage of life are diverse and differ from culture to culture. Comprehending the specific culture of the group being studied was, therefore, significant for research such as mine that has sought to identify the unique perceptions, thoughts and opinions of a group of people whose cultural knowledge was different to mine.

Coleman and Hendry (1990) argue that sociological, psychological and anthropological perspectives all have equal importance in understanding adolescence as they take into account all the factors that influence adolescent perspectives including reciprocity between the individual and the environment.

Subsequent to the current theories relating to adolescence and adolescent development this section of chapter two now presents how adolescence was defined for my research. This is followed by a discussion relating to research from the adolescent perspective.

Defining Adolescence

While it is important to discuss, albeit briefly, the theories that influence research into adolescence it is also relevant to position my research through a definition of adolescence. As Jaffe (1998) indicated, defining adolescence has always proved difficult. In the earlier part of the 20th century adolescents were thought to have attained adulthood when “they graduated from high school, joined the army, married, or simply left home” (Jaffe, 1998, p. 19). This altered in the late 1990s so that for the most part, the transition from adolescence to adulthood, along with attendant adult rites of passage in western society (such as driving a car) have been socially defined in terms of age without taking account of physical and emotional growth or sexual maturation (Jaffe, 1998). In Jaffe’s (1998, p. 21) opinion, using the criteria of age to determine the transitional period between childhood and adulthood provided an inadequate base on which to predict “emotional, cognitive and social maturity”. Jenks (2001) agreed with this argument but at the same time presented his own explanation that the transformation process from child to adult did not follow directly from physical growth or age criteria but was socially constructed through a multitude of variables.

I have taken account of these notions, but for simplicity with my research I have chosen to define adolescence in terms of that given by the Macquarie Dictionary which states that adolescence is “the transition period between puberty and adult stages of development; youth” (Delbridge et al., 2001).

The application of definitions or theories to research into adolescence as a stage of life does not detract from the fact that it is a time when the body undergoes dramatic growth and sexuality emerges bringing with it social mores and values regarding sexuality. Mental development achieves major transitions with the adolescent engaging in “analytic and metaphoric reasoning” (Adams, 2000, p. 2). It is a time of continuity and change in which developmental tasks and challenges require new modes of adaptation. According to Jaffe (1998), it is a time in which the adolescent is increasingly expected to adopt adult-like behaviours and responsibilities as precursors to becoming economically self-sufficient and independent. To this end adolescents are accorded specific tasks in the transition process that include:

...consolidating one's sexual identity and entering into sexual relationships, forming close, long lasting relationships with peers, setting goals and forming at least general ideas about occupational goals, separating oneself from one's parents by learning to take responsibility for one's own schedule and behaviour, learning to postpone the satisfaction of immediate needs in favour of long-term planning and goals, and for the first time, taking on at least partial responsibility for the welfare of others. (Robins, 1995, 367-368)

Research from the Adolescent Perspective

A literature search found that literature evoking the unique view of adolescents themselves is available, though it would appear to be limited in volume. This limitation is currently being addressed by proponents of the sociology of childhood and youth such as A.B. Smith, Taylor, et al. (2000). Furthermore according to Williamson (1996, p. 162) available literature associated with the adolescent viewpoint testifies "almost exclusively to the real inherent powerlessness of young people in controlling decisions about their own lives". It is, in effect, this paucity of research about adolescence by adolescents, which has been the driving force behind my research.

My research is concerned with the experiences of adolescents with AD/HD as they relate to their disorder, the use of stimulant medication and how they manage their lives. That is it focuses on the adolescent perspective. It is, therefore, appropriate for this chapter to extend its investigation from that of studying current dominant research methods to reviewing literature that purports to specifically relate to the adolescent perspective on adolescence.

In an attempt to seek out research that reported the adolescent point of view a study was made of articles in the Journal of Adolescence. Research relating to adolescents and adolescence appeared in a number of journals including those relating to Education and Psychology. The Journal of Adolescence was specifically chosen because amongst other perspectives, as its name implies, it presents research about adolescence. The assumption was made, therefore, that research presented in this journal would include research from the adolescent perspective. With this notion in

mind research was identified in the Journal of Adolescence that appeared from the title and abstract to indicate a focus on the adolescent point of view. A list of selected research is presented in Table 1. Table 1 presents only recent research, however, a search of previous years of the Journal of Adolescence drew similar results.

With the exception of the last study by Bergin et al. (2003) the other articles in Table 1 were based on research that was found, after detailed study of the contents, to be quantitative and employed standard questionnaires such as the Inventory of Parent and Peer Attachment, Young Adult Self Report and the Cognitive Emotion Regulation questionnaire. Questionnaires such as these have been developed from long standing theories, such as Erikson's identity model. Standardised questionnaires form part of the barrage of assessment tests utilised by psychological, sociological and anthropological researchers. These questionnaires consist of specifically directed closed questions that are used to elicit information, i.e., "I am unhappy, sad, or depressed" responses to be made according to a pro rata rated scale from 1 'not true' to 5 'very true' such as that of Likert (Grant et al., 2002, p. 614). Tests are assessed by appropriate sub-scales, e.g., SCL-90 (Symptom checklist), that seek to numerically identify differences and correlates by comparing mean scores and standard deviations. These subscales are based on long standing theories such as those related to self-blame. Research such as that of Grant et al. (2002) pre-empted adolescent perceptions by using adult-directed questions rather than allowing ideas and thoughts to emerge from what the adolescent was saying.

Table 1

Research whose title and abstract indicates a focus on the adolescent point of view⁴

Author	Date	Title
Stallard, Thomas and Churchyard	(2003)	<i>The mental health of young people attending a youth offending team: a descriptive study</i>
Olsson, Bond, Burns, Vella-Brodick and Sawyer	(2003)	<i>Adolescent resilience: a concept analysis</i>
Cote and Schwartz	(2002)	<i>Comparing psychological and sociological approaches to identity: identity status, identity capital, and the individualization process</i>
Garnefski, Legerstee, Kraaij, van den Kommer and Teerds	(2002)	<i>Cognitive coping strategies and symptoms of depression and anxiety: a comparison between adolescents and adults</i>
Grant, Marsh, Syniar, Williams, Addlesperger, Kinzler, et al.	(2002)	<i>Gender differences in rates of depression among undergraduates: measurement matters</i>
Meeus, Oosterwegel and Vollebergh	(2002a)	<i>Parental and peer attachment and identity development in adolescence</i>
Gullone and Moore	(2000)	<i>Adolescent risk-taking and the five factor model of personality, an Australian based study</i>
Greene, Kremar, Walters, Rubin, Hale, J. and Hale, L.	(2000)	<i>Targeting adolescent risk-taking behaviors: the contributions of egocentrism and sensation-seeking</i>
Bergin, Talley and Hamer	(2003)	<i>Prosocial behaviours of young adolescents: A focus group study</i>

⁴ This table has been reduced to single spacing so that it appears on one page for the convenience of the reader.

The exception was the study by Bergin et al. (2003) entitled '*Prosocial behaviours of young adolescents: A focus group study*'. Their research supports my argument that research into adolescence, for the most part, does not present the adolescent viewpoint. As Bergin et al. stated, "traditional research has not addressed the diversity of prosocial behaviours that youth enact, nor emphasized behaviours that are salient to young adolescents" (p. 13). It was their contention that future research in this field, to be effective, must include "a broad array of authentic behaviours of young adolescents ... systematically investigated in contextually meaningful settings" (p. 29) if it is to address the issue of prosocial development. To achieve this aim researchers are required to employ qualitative research methods and engage with the young persons themselves to elicit relevant realistic data (Galambos & Leadbeater, 2000). Meeus, Silbereisen and Nurmi (2002b) supported Galambos and Leadbeater commenting that the papers they studied concealed the silent voices of adolescents and characterised adolescence as a transactional transitional phase. Moreover, these papers concentrated on the adult perspective to explain adolescent identity and status (Meeus et al., 2002b). If these silent voices are to be heard, then as Christensen and James (2000) stated, adolescents should be permitted to actively interpret and reflect on the research in which they participate. In this way new insights will be gained into their own and other adolescent's social experiences and practices. That the voices of children and adolescents should be heard goes without question, embedded as they are in the contextual images of their family, school and neighbourhood and the broader community (Shaw, 1996; A.B. Smith. Taylor, & Gollop 2000). As Mayall (1994) and also Woodhead and Faulkner (2001) maintained adolescents like children are actors:

Interactive agents who engage with people, institutions and ideologies to forge a place for themselves in social worlds, and who, by demonstrating interactive skills, propose themselves as worthy of inclusion both as individuals and as a social group alongside adult individuals and groups. (Mayall, 1994, p. 7)

Discussion relating to the Adolescent Stage of Life

The intention of this section of chapter two is to furnish the reader with the background framework for the period of life known as adolescence from several different perspectives: the adult perspective; the current sociological, anthropological and psychological theories; the adolescent perspective and to present a definition of adolescence from the perspective of my research.

A broad discussion on the current literature discussing academic research into the adolescent stage of life concluded that research associated with adolescence and adolescent perspectives was for the most part based on the adult viewpoint and did not ask the open question to the adolescent of *what do they (adolescents) think?* Presently, research into adolescence remains cloaked in the fabric of anthropology, sociology and psychology from which the social construction of adolescence emanates and through which adolescence is seen and understood. As Woodhead and Faulkner (2001), Mayall (1994) and Oakley (1994) assert, the adolescent (and childhood) experience has been socially constructed.

The contention of this initial section of chapter two is, therefore, that as long as traditional sociologically driven notions remain the benchmark for contemporary perceptions of the culturally defined role of the individual, adolescence will continue to be perceived as a transitional process that requires adults to direct it. For "most social theories, through their emphasis on a taken for granted adult world, signally fail to constitute 'the child' as an ontology in its own right" (Jenks, 1982, p. 13). This viewpoint, expounded by Jenks in 1982, endured in his later work (1992; 2001) and appeared also in the work of A.B. Smith, Taylor, et al. (2000), Adams (2000) and Woodhead and Faulkner (2001). In practice, therefore, currently childhood and adolescence remain located within socialisation theories and "finds voice only as a distant echo of what it is yet to become" (Jenks, 1982, p. 14). As a consequence, the adolescents' experience of their social world, like that of children, remains one of social marginalisation (Adams, 2000; Amit-Talai, 1995; A.B. Smith, Taylor, et al., 2000; Woodhead & Faulkner, 2001).

I acknowledge that my search for research presenting the adolescence viewpoint was not exhaustive, however, it was extensive covering a search of articles in the Journal of Adolescence. My contention is, however, that notwithstanding this

my view is consistent with that of other researchers such as Bergin et al. (2003), Jenks (1982; 1992; 2001), Mayall (1994), Oakley (1994) A.B. Smith, Taylor, et al. (2000), to name but a few, who are of the opinion that presently there is only minimal research that presents the adolescent point of view.

As befits grounded theory research I have not presented research relating to the adolescent stage of life and adolescent development in great detail. As Glaser (1998) argued, in grounded theory there was a need for a researcher to be cautious about allowing literature and theories to direct thinking. Guided by Glaser's views on this matter I have sought to demonstrate the way in which adolescence and adolescent development is presently understood and the perspectives and theories that would appear to contribute to how this intelligence is conceived.

Attention-Deficit/Hyperactivity Disorder

Structure

The purpose of this second part of chapter two is to present literature associated with AD/HD from the perspective of its history, its diagnosis worldwide and in Australia and Western Australia. Heredity and gender factors and self-esteem, as well as the disorders comorbid with AD/HD will also be presented. Barkley's Unifying Theory of AD/HD will be discussed as well as stimulant medication usage, medication compliance in adolescence and multimodal treatments. Finally, this second section of chapter two will look at the risks and the social perceptions associated with the disorder. A summary of the first and second sections will conclude this chapter.

Introduction

The current diagnostic label for one of the most prevalent neurobiological/developmental disorders of childhood is AD/HD (American Psychiatric Association, 2000; National Institute of Health, 1998; Prosser & Reid, 1999; T.E. Wilens, Biederman, & Spencer, 2002). Recent evidence suggests that the disorder transcends the limits of childhood persisting into adulthood in 30 to 50 % of all cases (Barkley, 1998; Biederman, Faraone, Milberger et al., 1996; Gittelman, Mannuzza, Shenker, & Bonagura, 1985; Smalley et al., 2000). A 15-year longitudinal study by Barkley, Fischer, Fletcher and Smallish (2002), that examined the persistence of

AD/HD into adulthood from childhood, found that where self-reports were utilised persistence was rated low, at approximately 12%. If parent reports were used to identify persistence of AD/HD into adulthood from childhood then rates were much higher at 46-66%. In the opinion of Barkley, Fischer et al. (2002), the discrepancy between the self-report and parent reported persistence of symptoms of AD/HD into adulthood was because parents reports concentrated to a greater degree on major life-outcomes than self-reports. According to Barkley, Fischer et al. (2002), the findings of this research now brought into question the practice of relying on "proband self-report in adulthood to evaluate the persistence of AD/HD" (p. 29). They also suggested that changes might be appropriate in the symptom threshold for diagnosis of AD/HD in order to increase the sensitivity of diagnosis in adulthood.

Baumgaertel, Woolraich and Dietrich (1995) and Rohde et al. (1999) noted that AD/HD has also been recognised in different countries and the likelihood of its presence is not constrained by culture. The disorder contributes to 50 per cent of child psychiatric clinic cases (Cantwell, 1996; National Institute for Mental Health (NIMH) Office of Communications and Public Liaison, 2002) and has been and is the condition most commonly referred to psychologists in WA Schools (Langsford, Houghton, & Douglas, 1998).

For a condition such as AD/HD to rise to the level of a valid medical or psychiatric disorder it must be based on scientifically established evidence. According to Barkley (2001a), Jerome Wakefield a psychologist and philosopher of science, stipulated that a disorder is one that meets the criteria for harmful dysfunction. There must be evidence of a failure, a deficit or impairment of a mechanism that appears in all other humans – a mechanism that is universal to the species. Barkley contended that disorders are not solely failures of biological adaptation: heart, livers and brains etc. but also psychological mechanisms such as memory, language and inhibition. The ability to inhibit thought and action, which is a feature of AD/HD, is a mechanism universal to the human species. In Barkley's opinion, those with AD/HD are deficit in this mechanism of inhibition. Barkley contended, however, that for a deficit to be regarded as a disorder there must be impairment in a universal mechanism and the individual must be suffering as a consequence of the failure they have. For a child or adolescent to be clinically diagnosed with AD/HD they must exhibit inappropriate behavioural characteristics and be developmentally impaired, compared to those of

their age and gender, to such a degree that their impairment causes suffering (Barkley, 1998). As Barkley stated at a Sydney conference (2001a), "no suffering - no disorder, no impairment - no disorder". Barkley (2001a), Prosser (2000) and others acknowledge, however, that despite serious debate in both academic and popular discourses, with in excess of 6000 studies, controversy still arises on the origins, diagnosis and best treatment of those with AD/HD. This ongoing debate is, in part, explained by the tendency for young people with AD/HD to display considerable variation in the degree of their symptoms, its pervasiveness across situations and the extent to which other disorders are associated with the AD/HD (Barkley, 1998; Wilens et al., 2002).

The considerable body of research associated with AD/HD research has been, for the most part, quantitative in design. Those studies directed at ascertaining the opinions of those diagnosed AD/HD have usually focussed on boys aged between 6 and 12 years and taken the form of either self-report questionnaires completed by the children or double blind placebo-controlled medication trials involving self-assessments. Those studies seeking the adolescent perspective have also been largely quantitative with evaluation of outcomes presently benchmarked according to paper and pencil measures (i.e., adult rating scales), or double-blind placebo medication trials.

The rationale for using the above techniques could, in part, be due to the relative cost of those types of measures. According to Barkley (1981) and Robin (1998), however, research employing adult designed questionnaires was of questionable reliability. Questionnaires reflect the perceptions of those who construct them rather than allowing the perceptions of the participants to emerge from open-ended discussion. Questionnaires tend, therefore, to be biased in favour of those who construct them. As research into AD/HD is largely quantitative and uses adult directed instruments the unique thoughts and perspectives of adolescents' rarely emerge. Barkley (1981) and Robin's (1998) finding that AD/HD research with adolescents was adult centred rather than presenting the voice of adolescents was similar to research into adolescence noted in the first section of chapter two. This section noted that research into adolescence tended to be adult-centric rather than adolescent centred and the particular perceptions of adolescents related to their stage of life are seldom sought.

It should be noted, however, that recent studies involving adolescents with AD/HD undertaken by Cooper and Shea in the United Kingdom (1998) and Prosser (1998; 2000; 1999) and Hazell in Australia (2000; 1999; 1996) have endeavoured to redress this problem. The work of Hazell and Prosser has been of particular relevance to my research as their research has sought to present the perceptions of young people in Australia with AD/HD.

History of AD/HD

George Still first alluded to the core symptoms of AD/HD - developmentally inappropriate levels of attention, concentration, activity, distractibility and impulsivity - in the 1860s and they were formally recognised in 1902 (Spencer, Biederman, Wozniak, & Wilens, 2000). Still's symptoms according to Spencer et al. (2000), were not officially classified until 1937 when the disorder acquired the title of 'Minimal Brain Damage'. Over the course of the 20th century AD/HD has, variously been described as: Moral Defects of Moral Control, Minimal Brain Damage, Minimal Brain Dysfunction and Hyperactive Child Syndrome (Whiting, 1995). This last term, hyperactivity, was replaced by Attention Deficit Hyperactivity Disorder in 1987 in the Diagnostic and Statistical Manual of Mental Disorders-III-R (DuPaul, Guevremont, & Barkley, 1994). Currently, AD/HD is presented as a disorder of fronto-striatal-cerebellar networks (Castellano et al., 1996; Filipek et al., 1997; Zametkin et al., 1990, amongst others). This constant renaming of the same cluster of symptoms has understandably led to confusion in the medical profession, educationalists, parents and the general public.

Diagnosis of AD/HD: Overview

The current diagnostic criteria used to identify AD/HD are defined in The American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition -Text Revision (DSM-IV-TR™) (American Psychiatric Association, 2000). The DSM-IV recognises three subtypes: AD/HD combined type (AD/HD-CT), AD/HD predominantly inattentive type (AD/HD-PI) and AD/HD predominantly hyperactive-impulsive type (AD/HD-HI). According to DSM-IV-TR™, AD/HD prevails in childhood in the order of 3-10 %. Research by Milberger, Biederman, Faraone, Murphy and Tsuang (1995) and Pineda et al. (1999) had earlier come to the same conclusions. Prevalence has been found, however, to be as high as

15% to 24% (C. Whalen, 1989; Zentall, Harper, & Stormont-Spurgin, 1993). Boys were more likely than girls to be diagnosed with AD/HD (Barkley, 1998) and social skills deficits were noted in at least 50% of cases (Sagvolden & Archer, 1989). Barkley (1998) argued that gender differences in the diagnosis might be the result of studies incorporating smaller samples of girls than boys. Barkley (1996; 2001b) and Robin (1998) also argued that the difference in the numbers diagnosed in specific genders was because research was primarily carried out with boys and the symptom checklists in DSM-IV were developed empirically using young males, therefore, more males than females were identified as having AD/HD. If subsequent revisions of DSM-IV include more females then, perhaps, a more balanced checklist may result (Barkley, 1996). According to Bailey and Rice (1997) diagnosticians should, therefore, be aware that the DSM IV (American Psychiatric Association, 1994) criteria were established with research undertaken with six-year-old boys. In the opinion of Bailey and Rice and Barkley (2001b), the symptom checklists in DSM-IV (American Psychiatric Association, 1994) and the current version of the DSM-IV-TR™ (American Psychiatric Association, 2000) must be viewed in light of their deficiencies. According to Bailey and Rice (1997) and Barkley (2001b), it is inappropriate that pre-schoolers be compared with adolescents or adults as both versions of DSM-IV do now. As Barkley (2001a) contended when he spoke in Sydney, Australia, what was appropriate for a six year old boy was not appropriate to other age groups.

In Barkley's (1995; 2001a) opinion, a diagnosis of AD/HD should be made when behaviours within the normal continuum are exhibited more frequently and with greater intensity than other children of the same age and gender. Recent research presented by Wilens, Biederman and Spencer (2002) indicated that when a diagnosis of AD/HD was made by careful review of the symptoms and impairment it was both reliable and valid. Genetic imaging, neurochemistry, neuropsychological and biological data have supported their views (J. Biederman & Faraone, 2002; J. Biederman & Spencer, 1999).

It has been established that there is a substantial risk that children and adolescents with AD/HD will fail to achieve at school, fail to graduate from high school and under achieve in employment (Barkley, 1997c; Barkley, DuPaul, & McMurray, 1990; Robin, 1998; Tannock, 1998a). According to Robin (1998, p. 48),

the likelihood of AD/HD persisting into adolescence depended on three factors "1) familiarity of the ADHD, (2) family adversity and (3) presence of psychiatric comorbidity". The disorder AD/HD has been shown to persist through adolescence and into adult life in the order of 50% of cases, to an extent inappropriate for the age group, particularly where symptoms were severe and of early onset (Barkley, Anastopoulos, Guevremont, & Fletcher, 1991; Barkley, DuPaul et al., 1990; Barkley, Fischer, Fletcher et al., 2002; Cantwell, 1996; Gittelman et al., 1985). Barkley, Fischer, Edelbrock, & Smallish (1990) and Biederman (1997) viewed AD/HD as a persistent problem that was insidious in its intrusion into the social and educational life of the individual. Moreover, they regarded AD/HD as a great source of distress not only for the child, but also for their parents. Family environment, it has been contended, does not contribute significantly to the core symptoms of AD/HD (Barkley, Cook, et al., 2002). Nonetheless, issues such as: family environment, parenting skills, life stresses or deviant peer relationships will influence those with AD/HD as they do those without AD/HD. Disorders and problems comorbid with AD/HD, such as Anxiety Disorder, Oppositional Defiant Disorder and depression, related to social environment will also inevitably have an effect on those with AD/HD (Barkley, Cook, et al., 2002).

Diagnosis and Stimulant Medication use in AD/HD in Australia

This section specifically discusses the diagnosis and levels of stimulant medication use in AD/HD in the context of Australia and compares Australian findings with those of other areas of the western world. A study by Graetz, Sawyer, Hazell, Arney and Baghurst (2001) examined the validity of DSM-IV (American Psychiatric Association, 1994) AD/HD subtypes in Australia. Graetz et al.'s study assessed the diagnostic criteria of DSM-IV from the Australian perspective and concluded that the overall pattern of impairment found for DSM-IV (American Psychiatric Association, 1994) subtypes was "consistent with that reported by previous community based studies that used symptom checklists to identify ADHD subtypes" (Graetz et al., 2001, p. 1416).

Current prevalence of AD/HD in Australia was found to be 7.5% overall with AD/HD-PI being more common than AD/HD-HI and AD/HD-CT (Graetz et al., 2001). Graetz et al.'s findings supported an earlier study by Gadow and Sprafkin

(1997) in the USA. Gadow and Sprafkin's study had also noted that in their participant sample AD/HD-PI was more prevalent than AD/HD-CT and AD/HD-HI. According to Barkley (2001a), Gaub and Carlson (1997b) and Solanto (2002), those with AD/HD-PI were not behaviourally disruptive like their counterparts with AD/HD-HI or AD/HD-CT. Instead those diagnosed AD/HD-PI appeared as sluggish, underactive or daydreamy. Barkley (1998) contended that this disorder might not in actual fact be a subtype of AD/HD but another disorder entirely.

A study by Reid, Hakendorf and Prosser (2002) noted that the demographic characteristics of children receiving stimulant medication, and the overall patterns of use across age and gender for AD/HD were similar in both Australia and the USA. Reid, et al. found, however, that although the levels of stimulant medication use were lower in Australia, prescription rates varied widely across Australia. This view was corroborated by Berbatis, Sunderland and Bulsara (2002). Their study discussing stimulant medication consumption in Australia between 1984 and 2000 found that consumption of stimulant medication in Australia was high compared to other countries such as the U.K. Sweden, Spain, the Netherlands, France and Denmark with WA prescription rates ranking the highest of the States and Territories.

The overall prevalence rate for adolescents with AD/HD in Graetz et al.'s (2001) Australian study was 6.8%. Graetz et al.'s results were comparable to those of a Brazilian study with adolescents with AD/HD by Rohde et al. (1999). The overall prevalence figure for AD/HD in Australia was lower than indicated by studies outside Australia by Baumgaertel, Woolraich, Dietrich (1995), Gadow, Nolan Litcher et al. (2000) and Gaub and Carlson (1997a). The figures for the three studies quoted above ranged from 8% to 20%. The Australia study prevalence rate, however, was more in line with the prevalence figure suggested in DSM-IV (American Psychiatric Association, 1994). According to Graetz et al., the lower prevalence rate for AD/HD in the Australian study, compared to those studies undertaken outside Australia, was due to the Australian study requiring that additional DSM-IV criteria be met when making a diagnosis. Moreover, with the exception of Rohde et al.'s study, the other studies did not include adolescents.

In the opinion of Graetz et al. (2001), individuals with AD/HD-CT tended to be rated more impaired than the other two subtypes with greater social adversity than for those diagnosed AD/HD-PI and AD/HD-HI. Graetz et al. found, however, that

parents of children diagnosed AD/HD-PI indicated that their children experienced greater difficulties in number areas than those diagnosed AD/HD-HI. Parents also rated their AD/HD-PI children as having lower levels of self-esteem and more problems with their schoolwork and the teaching staff than those diagnosed AD/HD-HI. Children diagnosed with AD/HD-PI also experienced social rejection as they had a tendency to lack knowledge of social skills such as the social interactions required to join a group of children at play (Gaub & Carlson, 1997b; Graetz et al., 2001). Nonetheless, Graetz et al. found that the emotional behavioural problems and the psychosocial quality of life experiences of all three AD/HD subtypes were greater than those of the non-AD/HD controls participating in the study. Graetz et al., therefore, concluded that, as reported in DSM-IV (American Psychiatric Association, 1994), AD/HD was associated with pervasive impairment in multiple domains and affected not only individuals with the disorder, but also their parents and families.

Summary: Diagnosis and Stimulant Medication use in Australia

Diagnosis of AD/HD in Australia is based on DSM-IV (American Psychiatric Association, 1994). Prevalence rates in Australia for both children and adolescents were similar to those presented in community based studies worldwide at 7.5%. A diagnosis of AD/HD-PI was more prevalent in Australia than AD/HD-CT and AD/HD-HI. The findings of Graetz et al.'s (2001) Australian study were similar to those of other studies outside Australia that noted that those with AD/HD experienced impairment across multiple domains. Reid et al. (2002) study drew attention to the ongoing similarity of stimulant medication use for those with AD/HD between Australia and the USA. Stimulant medication use in W.A was, however, ranked highest of all the States and Territories (Bebatis et al., 2002). Identifying the similarities and differences in prevalence rates of AD/HD and levels of stimulant medication use between Australia and other countries in the western world allowed for my research to be viewed in context.

Diagnosis and Stimulant Medication use in AD/HD: The West Australian Perspective

Diagnosis of the core symptoms of AD/HD in WA may be made either by the use of DSM-IV (American Psychiatric Association, 1994) or International Classification of Mental and Behavioural Disorders - ICD-10 (World Health

Organisation, 1994). The current WA policy document relating to AD/HD entitled *Attentional Problems in Children* (The Office of Mental Health Department of Health Government of Western Australia, 2002), assessed the core clinical symptoms using DSM-IV and ICD-10 and affirmed the appropriateness of both these sets of criteria for the diagnosis of AD/HD in WA.

In WA prevalence of AD/HD has been found to vary according to the instrument or classification system employed, with no apparent gender differences. The Western Australian Child Health Survey (1995) found attention problems (as measured by the CBCL, Achenbach, 1991) in 5.5% of 4 to 11 year olds, rising to 7.6% in 12-16-year olds. According to the Australian Psychological Society position paper (Garton et al., 1997), however, this prevalence rate may have been over-estimated, depending on which measurement instrument was used. In 2002 the policy document entitled *Attentional Problems in Children* (The Office of Mental Health Department of Health Government of Western Australia, 2002) identified prevalence of AD/HD in school age children at 2-6 per cent, which was lower than the prevalence rates noted in Graetz et al. (2001). In the opinion of Berbatis et al. (2002) the differing methods used to assess AD/HD in Australia hinders the evaluation of prescribing practices and prescription rates in WA and in Australia in general. It was their suggestion that new countrywide standardised prescribing rates and practices may need to be established.

The *Attentional Problems in Children* policy document (The Office of Mental Health Department of Health Government of Western Australia, 2002) also outlined key strategies to improve outcomes for WA children diagnosed with AD/HD and associated disorders. This report also acknowledged "despite progress in assessment, diagnosis and treatment of ADHD, AD/HD and its treatment remained controversial" (The Office of Mental Health Department of Health Government of Western Australia, 2002, p. 19). The policy document also emphasised the need, prior to diagnosis of AD/HD, to obtain comparative data from home, school and general practitioners, with particular care being taken in the diagnosis with preschool children. A multi-disciplinary panel, chaired by Professor Hazell drew the same conclusions in their report (Hazell et al., 2000). This multi-disciplinary panel had earlier developed best practice guidelines for use in Australia for the diagnosis and treatment of AD/HD for professionals, including early childhood practitioners. The reports presented by the panel chaired by Hazell and the WA policy document would appear to offer medical

practitioners a clear set of guidelines for the diagnosis of AD/HD in Australia. The sentiments expressed in these two documents corresponded with those of other Australian studies by Graetz et al. (2001) and Hazell, McDowell and Walton (1996) as well as others outside Australia. Briefly, these sentiments were that DSM-IV criteria for AD/HD have been validated for young children. Beyond the early years, however, the stability of the diagnosis has not been substantiated; therefore, rigorous reviews must be implemented in later life. Domains of functioning need to be explored and a comprehensive assessment should involve the home, school and the medical profession. The assessment should also include attention being given to the possibility of comorbid disorders. Treatment directed at those with AD/HD, unless there has been evidence to the contrary, should be multimodal, with a regular review of treatment for children and adolescents by a diagnostician.

The Attentional Problems in Children policy (The Office of Mental Health Department of Health Government of Western Australia, 2002) expressed the view that:

ADHD is currently one of the most prevalent, costly and long-term developmental disorders in children in Western Australia. The cost to families and the community is high in both human and economic terms. The long-term prognosis for this disorder is poor with an estimated 70 per cent of children diagnosed with ADHD still having symptoms through to adolescence. (p. 24)

Summary: Diagnosis and Stimulant Medication Use in Western Australia

Diagnosis of AD/HD in WA may be made using DSM-IV (American Psychiatric Association, 1994) or ICD-10 (World Health Organisation, 1994). Prevalence rates for WA were 2-6% of school age children, however, these varied according to the diagnostic criteria employed. Although WA prevalence rates were lower than reported in the Graetz et al. (2001) Australia wide study. The Attentional Problems in Children policy document on AD/HD also stressed the need for specific criteria from DSM-IV or ICD-10 to be used in conjunction with data from home, schools and general practitioners when making a diagnosis. As with other areas of the world both Australia and WA regarded AD/HD as a significant developmental

disorder that affected children and adolescents and endured, in some cases, into adulthood. The disorder AD/HD was also found to impact on the home, school and social environment of diagnosed children and adolescents and their families.

Heredity, Gender and Self-esteem in AD/HD

Heredity and gender.

A considerable body of research has indicated that AD/HD is highly heritable in nature (Barkley, 1998; Biederman & Faraone, 2002; Levy et al., 1997; Smalley et al., 2000). According to Levy et al. (1997, p. 741), this finding is "robust in that it applies whether a continuum (trait) or categorical (diagnostic) approach is used to characterize ADHD, and even if different cut-off criteria are applied". Research undertaken by Biederman, Faraone, Keenan, Knee and Tsuang (1990); Biederman, Faraone and Lapey (1992); Gross Tsur, Shalev, and Amir, (1991); Pauls (1991); Smalley et al. (2000) and Welner, Welner, Stewart, Palkes, and Wish (1977) has shown that between 10% and 35% of immediate relatives of children with AD/HD will also be affected. Moreover, approximately 32% of siblings, of those with AD/HD and 55-92% of identical twins were at risk of having the disorder (Barkley, 1998, 2001a; Levy et al., 1997). More importantly and as research has demonstrated, the child of an AD/HD parent has a 57% risk of having AD/HD (Barkley, 1997a).

As previously indicated, boys are more commonly diagnosed with all three subtypes of AD/HD than girls are with the boy-girl ratio between 3 and 4:1 (Biederman, Faraone et al., 1999; Cantwell, 1996; Graetz et al., 2001; Swanson et al., 1998). The Australia-wide study by Graetz et al., however, found that although males predominated in all three subtypes in the Australian study the male to female ratio for AD/HD-HI (1.7:1) was somewhat lower and for AD/HD-CT (4.6:1) was higher than those figures quoted above. Research, however, has indicated a similarity between the genders in prototypic core symptoms of the disorder (J. Biederman et al., 1999; Garton et al., 1997).

On closer investigation research has indicated that many girls demonstrate the same underlying cognitive impairments as boys (T. E. Brown, 2000) yet, proportionally fewer girls than boys are diagnosed AD/HD. According to Biederman, Faraone et al. (1999), the potential for under-identification in females has substantial mental health and educational implications, particularly in the case of adolescent

females. Research undertaken by Rucklidge and Kaplan (2000) has indicated that apparently high levels of under diagnosis of AD/HD in adolescent females have brought with them considerable health risks (high rates of anxiety, depression and physical disease) in adulthood. The females who participated in the study undertaken by Rucklidge and Kaplan also indicated extreme feelings of helplessness in childhood as a result of the undiagnosed AD/HD (Rucklidge & Kaplan, 2000). This view is supported by Lyman (2002, p. 104) who demonstrated, not only was there a large pool of young women with undiagnosed AD/HD, but that these young women also had significant health problems. He attributed these poor levels of diagnosis of AD/HD in adolescent females (across all subtypes) to the lack of research with young women. A view supported by Barkley (2001a) and Rucklidge and Tannock (2001b) who asserted that the study of AD/HD in females, adolescents and adults presented a neglected area of research.

Self-esteem.

Low self-esteem, which is a core symptom of child and adult mood disorders, has been shown to be among one of the more enduring problems for those with AD/HD (Frankel et al., 1999).

Chia (2002) comments:

The tragedy of ADHD is the lack of self-confidence and esteem of children who have it. Because of poor attention-concentration span and inability to complete given tasks, often children with ADHD fail to perform well in their academic studies. This affects their self-concept. When a teacher or parent's focus *only* on what these children *cannot* do it becomes a self-fulfilling prophecy. (p. 1)

Earlier research by Rucklidge and Kaplan (2000) had reached the same crucial conclusion. Their research stated that there was a possibility that repeated experiences of failure in childhood and loss of self-esteem led to a learned- helplessness response in females. Rucklidge and Kaplan also stated that this learned-helplessness response in females in turn increased the likelihood of depression and anxiety becoming associated factors with AD/HD.

Few studies have employed objective self-report measures to assess self-esteem levels for individuals according to Slomkowski, Klein and Mannuzza (1995), despite evidence to show that high levels of depressive or anxiety symptoms occur in those with hyperactivity. According to Bussing, Zima and Perwein (2000), self-esteem levels for those with AD/HD were found to vary dramatically depending on the presence or absence of co-occurring problems such as depression or anxiety, thus highlighting the need for a comprehensive evaluation of child and adolescent functioning.

Frankel, Cantwell, Myatt and Feinberg (1999) and also Milich (1994) contended, however, that children with AD/HD who were prescribed stimulant medication as treatment reported higher self-esteem levels than those children with AD/HD who remained unmedicated. Popularity sub-scales for those children receiving stimulant medication showed "positive dose-response relationships with the total daily dosage of medication" (Frankel et al., 1999, p. 191).

According to Zubrick et al. (1997, p. 43), self-esteem refers to what an individual believes about themselves and where they stand within their society. In other words self-esteem is their image of self and feelings of self-worth. Adolescent studies carried out by Zubrick et al. have indicated that girls tended to have lower self-esteem scores than boys. Thirty-eight per cent of girls in global self-esteem scores were in the lowest third of the ratings compared with 27 % of boys (Zubrick et al., 1997). At the same time, adolescents reported feelings of school alienation associated with academic competence and mental health problems (Zubrick et al., 1997). A study by Rucklidge and Tannock (2001a) came to the same conclusion as Zubrick et al. when they identified a high ratio of females to males with anxiety and depressive symptoms and lower self-esteem. A further body of Australian studies undertaken by Sawyer, Whaites et al. (2002) and Waring, Hazell, T., Hazell, P, and Adams (2000) relating to quality of life supported the views of Zubrick et al. and those of Rucklidge and Tannock (2001a). Sawyer, Whaites et al. (2002) and Waring et al. (2000) emphasised the need for effective support mechanisms to assist young people to address their feelings of poor self-worth in order to improve their life outcomes.

Summary: Heredity, gender and self-esteem in AD/HD

Research has demonstrated that AD/HD is hereditary with boys more commonly diagnosed than girls, however, it was noted that females were a neglected area of research, therefore, it may be that females were under identified. All subtypes of AD/HD were associated with low levels of self-esteem. When anxiety or depression were comorbid with AD/HD self-esteem levels tended to deteriorate. A West Australian study by Zubrick et al. (1997) found that girls tended to have lower self-esteem scores than boys and adolescent girls expressed feelings of school alienation due to poor educational outcomes and mental health problems. Sawyer, Whaites et al. (2002) and Waring et al. (2000) came to the same conclusions as Zubrick et al. (1997), in addition, they suggested that there is a need for adolescents to have effective support mechanisms to overcome these feelings of low self-esteem and improve functioning.

Comorbidity and AD/HD

Ninety per cent of those with AD/HD have been found to have learning difficulties (LD) (T. E. Brown, 2000; Spencer et al., 2000) and anxiety and depression have been found to feature more highly in adolescents with AD/HD (J. Biederman, Newcorn, & Sprich, 1991).

Comorbidity is the co-existence of two or more disorders in an individual. Comorbidity of another disorder, as distinct and separate from physical conditions, with AD/HD has been demonstrated by research to be in the order of 50% of cases (Barkley, 1998; and also Langsford et al., 1998; Lyman, 2002; Robin, 1998; Spencer, Biederman, Wozniak, & Wilens, 2000). Numerous studies including those by Barkley (1998); Bird (1993); Biederman (1992); Pliska (1992); Robin (1998); Spencer (2000) have identified comorbidity of AD/HD with Conduct Disorder (CD), Oppositional Defiant Disorder (ODD) and Learning Disabilities (LD).

Research has demonstrated that LD tends to be comorbid with AD/HD in up to 92% of children (T. E. Brown, 2000; Spencer et al., 2000). Furthermore, research by Faraone, Biederman and Chen et al. (1992) and Light, Pennington, Gilger et al. (1995) indicated that where LD was seen as a discrete type, such as with reading disorder, common genetic factors influenced the likelihood of LD and AD/HD being comorbid. In addition, when a liberal rather than a strict definition of LD was applied then the

likelihood of LD AD/HD comorbidity was highest when relatives had AD/HD and LD (Faraone et al., 1992). According to B.H. Smith, Pelham, et al. (2000), screening for LD is of high importance, given that adolescents with AD/HD and LD performed significantly worse on measures of academic achievement, intellectual functioning and working memory, than for those with AD/HD who do not have LD.

Internalised or mood disorders such as depression, Anxiety Disorder and Bipolar Disorder have also been identified as being comorbid with AD/HD, with depression and anxiety occurring in the order of 15% to 75% of those diagnosed with AD/HD (J. Riederman & Faraone, 2002; J. Biederman et al., 1991). Merikangas, Avenevoli, Dierker, and Grillon (1999) reported, however, that family environment and parenting did not appear to be the determinants of whether children developed Anxiety Disorder in later life. According to Merikangas et al. (1999, p. 1523) "temperamental vulnerability factors for anxiety disorders in general may already be manifest in children prior to puberty". A study by Taylor, Chadwick, Heptinstall and Danckaerts (1996) also suggested that hyperactivity in young children was the precursor to impaired adolescent social adjustment. The issue of impaired social adjustment in adulthood for those with hyperactivity was of concern to Weiss, Hechtman, Milroy and Periman (2000) given the findings of their study that hyperactive young adults made significantly more suicide attempts than those who were not hyperactive. In the opinion of Hazell (1997b), paediatricians needed to be aware of and systematically seek out comorbidity of disorders when assessing patients, particularly in the case of AD/HD. According to Hazell (1997b), the significance of identifying multiple disorders in a patient was that each combination of disorders required a different management approach to address the problems being experienced.

The identification of AD/HD comorbid with depression and(or) Anxiety Disorder was of particular significance given the findings of a study in WA by Zubrick et al. (1997) which noted increased incidences of suicide and(or) deliberate self-harm amongst adolescents with mental disorders. Zubrick et al.'s study demonstrated that approximately 77 % of those adolescents who reported deliberate self-harm had a mental health problem. Zubrick et al.'s study also found that those adolescents who indicated having suicidal thoughts, or who attempted deliberate self-harm, generally were found to have lower self-esteem; with 47% of those who

reported thoughts of suicide being in the lowest 20% of self-esteem scores. Several studies reviewed by Townsend et al. (2001) supported Zubrick et al.'s findings and suggested that individuals with negative social experiences in their lives tended to exhibit a greater degree of powerlessness and hopelessness that may have led to an increased risk of suicide and/or deliberate self-harm. Given the low levels of self-esteem in those with AD/HD the association between AD/HD and comorbid disorders such as depression and Anxiety Disorder and attempted suicide is of concern particularly in adolescence where research has demonstrated that there are higher rates of attempted suicide than in other age groups. According to Hazell (2000, p. 539), there is a "need for systematic evaluation of treatments directed to adolescent suicide attempters. Attention needs also to be given to the style of services available to adolescents." Particularly, in light of recent research by Chan, Rey and Hazell (2002) that supported Hazell's (2000) views and questioned whether treatment guidelines for depression in young people, presented in the 1997 National Health and Medical Research Council recommendations (NH&MRC), are outdated.

The behavioural and academic difficulties associated with AD/HD and comorbid disorders are often so prominent that children's functioning in other areas, such as social functioning and quality of life, is often overlooked. For example, peer relations and emotional functioning, were often adversely affected with the presence of comorbid disorders exacerbating the problem (Bussing et al., 2000). Whalen, Jamner, Henker, Delfino, and Lozano (2002) reported from their study with adolescents, that those with AD/HD perceived that they had significantly more negative emotional experiences than their peers. The adolescents in Whalen et al.'s study also indicated that they were less happy than their peers and often resorted to smoking and drinking more than their peers. Whalen et al. noted, however, that the adolescent self-reports on their feelings did not correspond with parental reports. Whalen et al. suggested that parents of adolescents tended to underestimate the difficulties being experienced by their adolescent family members. In the opinion of Whalen et al., this discrepancy between the opinions of parents and adolescents indicated the necessity for clinicians to undertake a thorough assessment of the emotional functioning and well being of adolescents with AD/HD from the adolescents' perspective and for any problems identified to be attended to. As Chan et al. (2002), Hazell et al. (1996), Sawyer, Whaites et al. (2002) and Weiss et al. (2000)

argue, young people in Australia with mental disorders such as AD/HD, Anxiety Disorder, CD and ODD require assistance from multiple domains in order to enhance their emotional regulation, improve family relations and promote better life outcomes.

Summary: Comorbidity and AD/HD

The disorder AD/HD has been found to be comorbid with a variety of other disorders including Anxiety Disorder, depression, LD, CD and ODD. Zubrick et al. (1997) also noted that there was increased incidence of suicide or deliberate self-harm in adolescents with mental disorders. Given the low level of self-esteem in those with AD/HD particularly when there were comorbid disorders such as depression or Anxiety Disorder, the increased risk of attempted suicide in adolescents with mental disorders was of significance. Studies by Chan et al. (2002), Sawyer, Whaites et al. (2002) and Weiss et al. (2000) found that adolescents with AD/HD required assistance in multiple domains if they were to have improved quality of life. When AD/HD was comorbid with a disorder such as Anxiety disorder, CD or ODD then there was an even greater need for support.

Executive Functions and AD/HD

Executive functions (EF) is a term used to describe the primary mental functions that control the way in which an individual participates in their world. The disorder AD/HD is currently recognised as encompassing difficulties with sustained attention, distractibility, impulse control and hyperactivity (Barkley, 1990, 1995, 1997b; 1997c). Research undertaken by Barkley, (1997a; 1997b; 1997c; 2000) and Barkley, Koplowitz, Anderson, and McMurray (1997) argue that the central deficit is one of impaired behavioural inhibition. Barkley (2000) contends that recent years have witnessed rapid growth in the understanding of the function of the regions of the brain, in particularly the prefrontal cortex. This expansion of knowledge has enabled researchers to appreciate how "this region of the brain regulates specific mental activities that allow for self-control". According to Barkley (1997a; 1997b; 1997c; 2000) and Barkley, Koplowitz et al. (1997), those with AD/HD experience a deficit in self-control that affects EF. These EFs control self-regulation, working memory (sense of time, past and future), syntax and individual ability to reprocess complex behavioural sequences.

In the opinion of Lezak (1995, p. 42), EFs refer to “those capacities that enable a person to engage successfully in independent, purposive, self-serving behaviour”. These EFs refer to the “when” and “whether” of behavioural action, whereas, non-executive functions comprise the “what” and “how” of action. According to Barkley (2000), many theorists such as L.S. Vygotsky and Stuart Dimond acknowledge that EFs extend over or are interchangeable with self-regulation and may influence an individual’s day-to-day management of social behaviour. In Barkley’s (2000, p. 1065) opinion, EFs seem to involve: “volition, planning, and purposive, goal-directed or intentional action; inhibition and resistance to distraction; problem solving and strategy development, selection and monitoring; flexible shifting of actions to meet task demands; maintenance of persistence toward attaining a goal; self-awareness across time”.

Barkley (1997a; 2000) contends that there are four areas of EF: non-verbal working memory, verbal working memory, internalised emotion/motivation and reconstitution. In Barkley’s (1997a) opinion, individuals with AD/HD have impaired response inhibition this deficit leads to secondary impairment in the four areas of EF detailed above. In order to explain his thinking Barkley (2000) detailed each of these areas.

1. Non-verbal working memory comprises visual imagery and private audition. Non-verbal working memory allows an individual to maintain a mental representation (retrospective function) of an action in order to guide future behaviour (prospective function). In other words non-verbal working memory allows an individual “to remember in order to do” (Barkley, 2000, p. 1065) and to be able to sustain this memory of a past action to a future time so that self-directed action conforms with socially expected conduct.
2. Verbal working memory is the developmental progression from speech towards others to speech to self as internalised language. According to Barkley, the motor control of language arises in the area of verbal working memory (2000). Together verbal and non-verbal memory control comprehension and conformity to social mores, values, expectations and conventions through a process of internalised rules.

3. Internalised emotion/motivation, this area is the seat of self-regulation (SR) and “may arise, at least initially, as a consequence of the first two EFs” (Barkley, 2000, p. 1067). SR is a significant aspect of EF as it allows an individual to inhibit immediate response and, therefore, control future response and consequence (Barkley, 2000). Emotional and motivation states occur when an individual moves from speech towards others to recreate visual and verbal mental stimuli as internalised language. In the first instance, a child may verbalise thoughts or experiences aloud, later as the child matures it adapts to internalise thoughts and experiences as non-vocal covert private speech. SR can only eventuate with response inhibition in that response inhibition permits the “internalisation or privatisation” of EF. With this EF the individual moves to inhibit immediate response and control future response and consequences as SR action. According to Barkley (2000), Dimond and Vygotsky asserted that the EF/SR system evolved to facilitate individual social adaptation and is, therefore, the site of social intelligence.
4. Reconstitution which comprises syntax and the individual ability to reprocess complex behavioural sequences. Reconstitution most probably arises from play according to Barkley (2000). Barkley suggested, “it is a form of ideational Darwinism in which the units of old experiences are recombined into novel behaviour that is judged against the goal to be attained so as to select the most viable option” (2000, p. 1067).

These four EFs furnish the individual with “a powerful set of tools” (Barkley, 2000, p. 1067) to regulate self and direct future social exchange. This argument has evolved into a theory, which is referred to by Barkley as the Unifying Theory of AD/HD (1997a; 1997b; 1997c; 2000).

The EFs “act in concert to achieve the overarching goal of a net maximization of long-term social (economic) rather than more immediate outcomes for the individual” (Barkley, 2000, p. 1066). Without self-regulated EF and the ability to control self-directed action over time there is a probability that an individual with AD/HD may fail to meet social mores, values, expectations and conventions.

Barkley (1997a; 2000) and Barkley, Koplowitz et al. (1997) argue that it is impairment of EFs that contributes to the problems (e.g., calling out in class, or failing

to carry out tasks, in school or in the home) experienced by many individuals with AD/HD. Barkley (2000) also has suggested that the symptoms related to AD/HD are not so much deficits of attention but deficits of intention. According to Klorman et al., (1999), deficits in executive function are central to AD/HD. In Klorman et al.'s opinion, however, these deficits are not induced by comorbid disorders such as Oppositional Defiant Disorder or Learning Disorder (specifically that attributed to reading). Being deficit or impaired in EF affects not just the social and educational outcomes for an individual with AD/HD, but also whether that individual is accepted by society (Barkley, 1997a; 2000). Martin, Earleywine, Blackson and Vanyukov (1994) had previously expressed similar concerns in their earlier research that established substantial evidence to show that executive functions were important determinants of behaviour.

According to Hutchins (2002), because of the complexity of EF impairment, that are largely cognitive and covert, extensive self-report data from those with AD/HD relating to history and the ability to organise complex everyday tasks are important sources of information. Brown (2000) previously expressed the same view, stating that in light of the high level of frustration and the emotional impact deficits have in executive function have over social functioning for those with AD/HD, being aware of their views and needs was of consequence. These notions were particularly relevant for my research given that the focus was to identify the social experience of a small group of adolescents with AD/HD and how they manage their lives.

Not all AD/HD theorists, however, appear totally convinced of the exactness of Barkley's Unifying Theory of AD/HD (1997a; 1997b; 1997c; 2000). For example, the results of a meta-analysis conducted by Ossterlaan, Logan and Sergeant (1998) demonstrated that executive function deficiencies were not specific to children with AD/HD disorders since they were also evident in children with Oppositional Defiant and Conduct Disorders. Sergeant (1998) proposed a Cognitive-energetic Model of AD/HD; this model was previously described by Saunders (1983). Sergeant's model observed deficiencies in AD/HD from three distinct levels: a lower set of cognitive processes (i.e., encoding, central processing and response inhibition); the energetic pools of arousal, activation (i.e., the control of motor readiness) and effort; and the management or EF system (Sergeant, 1998). According to Sergeant, primary deficits of AD/HD occurred when an individual's functional state is at variance with the

individual's cognitive energetic state and as a consequence additional effort is required to resolve issues.

The appropriateness of a single core deficit model of AD/HD, such as Barkley's Unifying Theory of AD/HD, was also challenged by Sonuga-Barke (2002) who suggested the possibility of multiple causal pathways. Sonuga-Barke contended that the single core deficit model furnished insights into the various components of AD/HD but did not reflect the possibility that multiple neuro-psychological pathways may share elements at a neuro-chemical or anatomical level. Sonuga-Barke proposed a Delay Aversion Model of AD/HD. This model proposed that AD/HD was essentially a situation specific, motivational disorder in which a child's inattentive, overactive and impulsive responses were not actively suppressed by choice rather the child sought immediate experience gratification.

Summary: AD/HD and EFs

Barkley's Unifying Theory, one of the most comprehensive theories proposed to date, places executive functions and specifically behavioural inhibition and self-regulation at the forefront of determining the effectiveness of an individual's functionality (Barkley, 2000). Sergeant (1998) argued, however, that EF deficits were not solely found in those with AD/HD. Moreover, Sonuga-Barke (2002) contended that Barkley's Unifying Theory of AD/HD did not take account of the multiple causal pathways for AD/HD. While other theorists have challenged Barkley's Unifying theory or advanced differing notions, in the context of my research Barkley's theory presents a logical pathway to explain and understand individual action and reaction in society.

According to Barkley (2000), EFs are influenced by self-control and response inhibition (self-regulation). Barkley argues (1997a; 1997b; 1997c; 2000; Barkley et al., 1997) that without self-control and response inhibition the secondary areas of EF, non-verbal working memory, working memory, internalised emotion/motivation and reconstitution are compromised. Research has demonstrated overwhelmingly that individuals with AD/HD have a deficit in behavioural response inhibition. Consequently if, as this Unifying Theory would appear to have suggested, those with AD/HD experience deficits in response inhibition (self-regulation and social intelligence) then their ability to function effectively within social and educational

expectations (to conform) is compromised. Hutchins (2002) and Brown (2000) suggested that given the complexity of the disorder, self-report data from those with AD/HD would be beneficial to research, particularly, when research was directed at assessing the impact of AD/HD on the lives of those with the disorder.

Stimulant Medication and AD/HD

The role of stimulant medication in AD/HD is the arousal of activity and alertness in the central nervous system (CNS) (Barkley, Grodzinsky, & DuPaul, 1992; DuPaul, Barkley, & Connor, 1998). These drugs mimic the natural brain catecholamines or neurotransmitters dopamine and norepinephrine. It is believed that stimulant medications enhance catecholamine activity in the CNS; nonetheless the precise mechanism of their action is still poorly comprehended. The efficacy of stimulant medication, as against other types of child therapy for AD/HD, is well documented (Barkley, 2001b; Barkley, Fischer, Fletcher, & Smallish, 2003; Conners, 2002; DuPaul et al., 1998). The National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, (1999) which undertook a 14 month randomised clinical trial of treatment strategies for AD/HD with a group of children aged 7 to 9 years 9 months, found an appreciable reduction over time for most AD/HD symptoms with stimulant medication treatment. The MTA Cooperative Group findings indicated that medication treatment proved superior to intensive behavioural treatment and community care for treatment of AD/HD. With a few exceptions, a combination of stimulant medication and behavioural therapy did not significantly improve outcomes for AD/HD core symptoms compared with stimulant medication alone (National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999). The MTA Cooperative Group study found, however, that combined stimulant medication and behavioural therapy may "provide modest advantages for non-AD/HD symptoms such as: oppositional/aggressive symptoms, internalizing [*sic*] symptoms, teacher rated social skills, parent child relations, and reading achievement" (p. 1073) and lead to positive social and educational outcomes.

Despite pharmacological intervention through the administration of psycho-stimulant medications being widely recommended and accepted by the medical profession as the primary means of treatment for AD/HD (Barkley, 2001b; Barkley et

al., 2003; Conners, 2002; Greenhill et al., 1999; National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999) there are those who remain sceptical about the use of stimulant medication. Breggin (2001; 2002) and Klein (2001) for example, question the validity of the MTA Cooperative Group study on the grounds that the MTA study was not a placebo-controlled, double blind, clinical trial. Moreover, of the 4,541 children originally screened, only 12.8% (579) entered the study and only 2.7% (123) completed the medication management trial.

The stimulant medications Dextroamphetamine, Methylphenidate and Pemoline, which are prescribed for those with AD/HD, share the same side effect profiles. These include decreased appetite, insomnia, stomachache, headache and irritability. The majority of side effects experienced by those with AD/HD will decrease over time, some individuals, however, respond to one stimulant medication more favourably than another (Cantwell, 1994; Greenhill et al., 1999; National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999). Concern that growth suppression was associated with stimulant medication usage had little evidence in long-term studies (Cantwell, 1994; Greenhill et al., 1999; National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999). Research also demonstrates that the medication appears to be as effective in puberty as in early childhood and that tolerance to medication does not develop or lead to substance abuse (Barkley, Fischer, Fletcher & Smallish, 2003; Greenhill & Setterberg, 1993; Klein & Mannuzza, 2002). Moreover, a meta-analysis of literature relating to stimulant medication usage in AD/HD and the risk of substance abuse found that "stimulant therapy in childhood is associated with a reduction in the risk for subsequent drug and alcohol use disorders" (T. E. Wilens, Faraone, Biederman, & Gunawardene, 2003, p. 179). The WA policy document on Attentional Problems in Children (The Office of Mental Health Department of Health Government of Western Australia, 2002) noted, however, that recent research indicated a correlation between substance abuse in adolescence and adulthood and untreated AD/HD.

Volkow, Fowler, Wang, Ding and Gatley (2002) asserted that Methylphenidate was the most commonly prescribed drug for the treatment of AD/HD. A review by

Connors (2002) on forty years of Methylphenidate treatment for AD/HD found that many studies consistently presented the same evidence; i.e., that Methylphenidate treatment has a significant impact on the core symptoms of AD/HD. Connors also indicated that to date, research would appear to support the perception that Methylphenidate treatment was as affective for older adolescents and adults as it was for younger individuals, however, improvement in AD/HD symptoms in older individuals was dose-dependent (J. Biederman & Spencer, 2002). Connors (2002) and Biederman and Spencer et al. (2002), however, suggested that further studies with older adolescents and adults were required to identify long-term effects in older populations.

Within Australia, unlike the USA, Dexamphetamine is currently the preferred medication over Methylphenidate. This difference may in part be explained by the fact that Dexamphetamine is listed on the Australian Pharmaceutical Benefits Scheme and is, therefore, a subsidised medication and Methylphenidate is not (National Institute for Mental Health (NIMH) Office of Communications and Public Liaison, 2002; Prosser, 1997). Research by Sawyer, Rey et al. (2002) and the WA policy document on Attentional Problems in Children (The Office of Mental Health Department of Health Government of Western Australia, 2002) found that 13% of children with AD/HD in Australia were taking stimulant medication.

Regardless of which stimulant medication was utilised, medication must, according to Rapport (1992, p. 159), "be carefully titrated on an individual basis to maximize therapeutic outcome and that such outcome should seek to avoid compromising cognitive function at the expense of behavioral improvement". Careful titration of medication was particularly relevant, as cognitive toxicity had been reported in a subgroup of patients at doses at which the behavioural effects of medication were maximised (Cantwell & Swanson, 1992).

The literature suggested that social interaction between children with AD/HD, their parents, teachers and peers was significantly enhanced by stimulant medication. Stimulant medication, it was maintained, increased the acquiescence of the child with AD/HD to parental commands and elevated their interactive response and diminishes negative behaviours. For example, research indicated that behavioural compliance by the child with AD/HD led to raised levels of positive response in parents and teachers, simultaneously compliance decreased the rates of command and supervision levels

(Barkley, 1998; DuPaul et al., 1998; Schubiner, 1998). Research also demonstrated that the acceptance of the child with AD/HD by their peers was to a small degree enhanced by stimulant medication (Whalen, 1989). Studies indicated, however, that stimulant medication resulted in a marked improvement in negative and aggressive behaviour of the child with AD/HD towards their peers (Whalen). According to DuPaul et al. stimulant medication not only directly affects the behaviour of the child with AD/HD, but is also indirectly responsible for changes in parent, teacher and peer attitudes. In the opinion of DuPaul, et al. changes in the attitude of parents, teachers and peers to those with AD/HD may have contributed to an increase in positive drug response from those children with AD/HD. Nevertheless, as Schubiner and previously Sleator et al., (1982) argued, it was important for physicians to emphasise to patients and parents that medication can and should be used only as an aid to facilitate the child or adolescent to help themselves.

The significance of stimulant medication for those with AD/HD is that without this chemical intervention it is difficult for the majority of adolescents to make the behavioural changes necessary to allow them to participate effectively at school and in the home and to feel good about themselves (Cantwell, 1996; Schubiner, 1998). Stimulant medication, it has been argued, improves cognitive function, response inhibition and self-regulation for those with AD/HD (Barkley, 2001b; Hutchins, 1997; Rapport & Kelly, 1993; Tannock, Schachar, & Logan, 1995) and enhances other treatments such as behaviour modification (Hutchins, 1997).

Nonetheless, according to Barkley, Cook, et al. (2002), any benefits from treatment are compromised where there are specific problems associated with AD/HD and stimulant medication usage (e.g., low self-esteem, poor education and social outcomes and family stress). Benefits from stimulant medication therapy are particularly jeopardised when the problems experienced by those with AD/HD and their families are socially mediated (Barkley, Cook, et al., 2002; Faigel et al., 1995). For example, research has indicated a tendency for some teachers to discount AD/HD as the basis of academic and behavioural difficulties in children and instead blame "poor parenting" for the problems encountered with the children in school (Frank, 2000). Prosser (1997) suggested that teachers were suspicious about the diagnosis of AD/HD. Teachers' suspicions about AD/HD diagnosis stemmed from the knowledge that pressure to succeed in school was high and that many students did not have the

ability to meet these demands. A diagnosis of AD/HD was, therefore, seen as a way of excusing problems associated with academic outcomes (Prosser, 1997). According to Frank (2000), some of the problems experienced with teachers by those with AD/HD were because teachers vary dramatically in their ability to work effectively with students with AD/HD. There were those teachers whose knowledge and understanding of the difficulties created by AD/HD and the strategies for assisting children was of a high order. Other teachers, however, had only minimal knowledge and understanding of the disorder.

Controversy in medical profession about AD/HD and the use of stimulant medication (Barkley, Cook, et al., 2002) also contributed to negative social perceptions. For example, the following statement was made in a West Australian child and adolescent health journal "It (AD/HD) is associated with urban living, institutional care and social deprivation" (Jausar & Sarfraz, 2002, p. 31). This quotation reaffirmed Prosser's (1997) point, that within the medical profession disagreement still exists over the extent to which environmental factors play a part in behavioural issues related to AD/HD. In other words symptoms of AD/HD were attributed to the environment and not the result of deficits in response inhibition and executive function. Issues such as these coupled with the problems and frustrations experienced by children and adolescents with AD/HD and their parents become further exacerbated when there is an inadequate level of communication between the relevant involved agencies - i.e., the parents, the medical profession, teachers and allied health professionals (Doherty, Frankenberger, & Fuhrer, 2000; Hutchins, 1997).

In Hutchin's (1997) opinion, poor levels of professional collaboration in AD/HD amongst the involved agencies are not only detrimental to those professionals involved with children and families with AD/HD, but poor professional collaboration also tends to seriously increase the suffering of the child and their family. In Hutchin's (1997) view, this failure of involved agencies to collaborate is said to be due on the one hand to insufficient understanding about the disorder AD/HD in some instances and on the other hand to a lack of professional insight into each other's perspectives and professions.

Medication compliance in adolescence

Low compliance levels in medication treatment for adolescents with AD/HD represented yet another issue to be addressed (Dulcan & Benson, 1997; Garland, 1998; Greenhill et al., 1999; B.H. Smith, Pelham, et al., 2000). Barkley (2001b) and Robin (1998) suggested that it is not uncommon for adolescents with AD/HD to express the view that they do not need medication treatment and to refuse to take it. According to earlier research by Sleator et al., (1982) these findings were consistent with other research that suggested adolescents do not utilise prescribed medication. In the opinion of Brown, Borden, Wynne, Spunt, and Clingerman (1987), inadequate medication compliance was pervasive in paediatric medicine. Research has also demonstrated that where patients were of a low socio-economic status there was supporting evidence to suggest a greater risk of medication non-compliance (R. T. Brown et al., 1987). The problem experienced with compliance in AD/HD by clinicians was further exacerbated by the long-term nature of the treatment regime for the disorder (Greenhill et al., 1999).

According to adolescents with AD/HD medication non-compliance during adolescence was based on several factors including the affects of stimulant medication, described by adolescents as creating a 'zombie like' state and social and peer reaction to stimulant medication (Bowen et al., 1991; Landau & Moore, 1991; Polis, 2001). Other side effects reported by adolescents were "makes me nervous and psycho;" "sometimes I get headaches and I always have a bad temper at home after taking Dexedrine" (Doherty et al., 2000, p. 49). The general problems associated with poor medication compliance rates in adolescence were two-fold. First, adolescents "with AD/HD exhibited a pervasive dislike for taking stimulant medication (Robin, 1998; Sleator et al., 1982) and second, the experience of adolescents relating to stimulant medication was less than positive particularly if there was poor treatment management (Doherty et al., 2000).

Tracey and Gleeson (1998) expressed the opinion that social and personal problems experienced by adolescents with AD/HD cannot be addressed without the direct involvement of the adolescents themselves to resolve issues or problems. Hazell, Lewin, McDowell and Walton (1999) suggested that in order to foster better outcomes for those with AD/HD parents, teachers and the young people themselves needed to be made aware of information relating to AD/HD, particularly in the context

of stimulant medication. Hazell et al. (1999) and Hazell et al. (1996) were also of the opinion that treatment review intervals of less than six months for those with AD/HD may be appropriate. According to Whalen (2001, p. 136), research is needed to examine ways of improving outcomes beyond stimulant medication, "using systematically tailored and sequenced psychosocial approaches and exploring new treatment targets, agents, and modalities". As Barkley pointed out in 1998 and more recently in 2001, however, "no other treatment for ADHD has been subjected to so much empirical scrutiny as medication, particularly stimulant medication" (1998, p. 225).

Medication compliance in adolescents, according to Robin (1998), was a very under researched area. Doherty et al. (2000) also attested to the need for further study to ascertain adolescents' perceptions of the positive and negative effects of stimulant medication and the effects on adolescents of parents' and teachers' attitudes towards stimulant medication. With Doherty et al.'s considerations in mind, research by B.H. Smith, Pelham, et al. (2000) that evaluated the perceptions of adolescents with AD/HD as regards the effectiveness of their medication treatment, has potentially important implications for how the treatment of adolescents with AD/HD may be monitored. B.H. Smith, Pelham, et al.'s research, undertaken at an eight-week summer treatment programme, established that adolescents with AD/HD were better able than their teachers to recognise how they were getting along with their peers and the staff. Whereas, teachers were better able to assess competence ratings for AD/HD specific symptoms such as 'attending in class' than the adolescents.

Summary: Stimulant Medication and Medication Compliance in Adolescence

Available research has indicated that when carefully planned, the single most effective treatment found to ameliorate the significant problems experienced by those with AD/HD was stimulant medication. Research also indicated that there was no conclusive evidence for long-term harm from stimulant medication usage (Barkley, 1997a; 2001c; DuPaul et al., 1998; Garland, 1998; Greenhill et al., 1999; National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999). Biederman and Faraone (2002), Conners (2002), Doherty (2000) and Garland (1998) nevertheless, suggested that there was a need for further long-term research to determine the outcomes of sustained

usage of stimulant medication, particularly in the case of adolescents and adults with AD/HD.

A lack of medication compliance in adolescents with AD/HD, identified in research by Barkley (1998), Robin (1998) and others, emphasised the need for research to be conducted with adolescents with AD/HD. There were fundamental reasons for undertaking research with adolescents with AD/HD. These were: 1) to ascertain their experiences about stimulant medication and 2) to address their needs and problems as they see them.

This review of stimulant medication has not intended to discount other forms of treatment such as behaviour and cognitive therapy and psychosocial counselling. Rather, because all the participants in my research were receiving stimulant medication as a form of treatment, I considered it appropriate to specifically review research related to the use of stimulant medication.

Multi-modal Treatment with AD/HD

A host of studies have endorsed the ability of both pharmacotherapy and behaviour therapy to treat the symptoms associated with AD/HD (Abramowitz, Eckstrand, O'Leary, & Dulcan, 1992; Cantwell, 1996; Schubiner, 1998). Research has also demonstrated that for some children, intense behavioural intervention can achieve comparable results to that of medication (Abramowitz et al., 1992). Subsequent research by Barkley (1998), Cantwell (1996), Robin (1998) and Schubiner (1998) would appear to indicate that if normalisation of behaviour, as the literature would appear to indicate, was the aim of treatment for those diagnosed with AD/HD then a combination of optimal doses of medication and behavioural intervention would appear to be appropriate. Nonetheless, as Faigel, Sznajderman, Tishby, Turel and Pinus (1995) commented in their review of Attention Deficit Disorder during adolescence:

Whereas the precise combination of these interventions varies with the needs of the adolescent and the family ... no one approach, neither medication nor psychotherapy, is sufficient and combined multimodal treatment extending over long periods of time produces great gains. (p. 176)

Longitudinal studies with children who have AD/HD have demonstrated the efficacy of multimodal treatment strategies (including stimulant medication usage) with significant improvement in antisocial behaviour and inattentiveness where treatment continues over an extended period of time (say 9 to 34 months) (Greenhill et al., 1999; Jarman, 1992; Satterfield, Satterfield, & Cantwell, 1981). A recent long-term study by the MTA Group (1999), however, would appear to indicate the contrary. Their research with combined treatment came to the conclusion that it "did not yield significantly greater benefits than medication management for core ADHD symptoms" (National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999, p. 1073).

The Risks Associated with AD/HD

Studies by Barkley and others in the USA indicate that children and adolescents with AD/HD are at significant risk of under achievement and under productivity in school, with 35-50% of children with AD/HD being retained in grade as opposed to 10% of children without AD/HD⁵. Suspensions and expulsions, due to conduct problems, are significant issues, with 49% of children with AD/HD (non AD/HD 15%) affected; moreover 10% of children with AD/HD left school prior to completion. In later life 50% of those with AD/HD are likely to under achieve in employment (Barkley, 1997c; 1998; Gilberg et al., 1997; Rubinstein & Brown, 1981). Jensen and Abikoff (2000, p. 641) concurred with these views stating that severe AD/HD symptoms in children and adolescents may lead to poor academic outcomes and the danger of being suspended or expelled. These figures quoted above are taken from studies outside Australia, however, the many Australian studies quoted in this background chapter attest to their validity (Hazell, 1997a; Hazell et al., 2000; Hazell et al., 1999; Hazell et al., 1996; Prosser, 1997, 1998, 2000; Prosser & Reid, 1999; The Office of Mental Health Department of Health Government of Western Australia, 2002).

Adolescence is well documented as a time when individuals are faced with new tasks and challenges, however, it is also seen as a time of increased risk-taking

⁵ In Western Australia schools Education Department Policy does not support young people being retained in grade (Education Department of Western Australia, 1999) grade retention rates are not, therefore, recorded in Western Australian statistics.

behaviour. Risk-taking behaviours arise on the one hand because adolescents tend to have a heightened sense of invulnerability and on the other hand adolescents believe they need to impress their peers and see risk-taking behaviour as a way of achieving their aim (Bjorklund, 1995; Kazdin, 1989; Rice, 1992). For the adolescent with AD/HD, these tasks, challenges and behaviours take on more serious meaning from those of younger children (Barkley, 1998). According to Barkley (1998) and Robin (1998) and also Woodward et al. (2000), adolescents with AD/HD have been shown to demonstrate a higher level of risk-taking behaviour than their peers without AD/HD. In addition, families who have an adolescent with AD/HD have been found to experience greater stress and conflict than was normally associated with adolescence (Robin, 1998). Moreover, adolescents with AD/HD experienced peer relationship problems, with a few being friendless (Jensen & Abikoff, 2000; Rotenberg & Hymel, 1999). According to Frankel et al. (1999) and Parkhurst and Hopmeyer (1999), it is the biological deficits present in AD/HD which tend to result in low self-esteem that may indirectly contribute to their friendless state and concomitantly to their loneliness. This is particularly the case when peer rejection and social rejection occur due to behaviours regarded as unacceptable. Robin (1998, p. 21) concurred with these views stating, "clinicians should not underestimate the tremendous negative impact of low self-esteem and sadness resulting from life failure experiences caused by ADHD". The issue of low self-esteem and the association between it and attempted suicide, particularly where depression and Anxiety Disorder are comorbid with AD/HD were concerned, was discussed earlier. Suffice to say that self-harm or even attempted suicide was and is a risk for adolescents with AD/HD that should not be discounted. Adolescents with AD/HD like others with AD/HD need the support of their friends, family, school and society.

Summary: Risks and AD/HD

Studies indicated that those with AD/HD were at risk of failing in school, have poor relationships with their peers and were in conflict with society. Low self-esteem contributed to the adolescent with AD/HD feeling unloved and unwanted. Clinicians needed to be aware of this, particularly as adolescence was seen as a time of new tasks and challenges that were more difficult for those with AD/HD. It is the nature of adolescence to demonstrate risk-taking behaviour. Adolescents with AD/HD, however, are at particular risk of experiencing problems given that they tend to exhibit

higher levels of risk-taking behaviour than their peers without AD/HD. Adolescents with AD/HD require the support of their friends, family, school and society if they are to succeed in their lives.

Social Perceptions of AD/HD

According to Barkley, Cook, et al. (2002) and DuPaul, Barkley & Connor (1998), media hysteria in the late 1980s and 1990s that accused parents and doctors of drugging children into submission may have been responsible for the wave of media stories concerning increased rates of Ritalin, (Methylphenidate) prescribing. More recently the "public atmosphere of concern and even alarm" (DuPaul et al., 1998, p. 511) related to stimulant medication (in particular Methylphenidate - Ritalin) prescribing for AD/HD may have been brought about through recent television reports of stimulant abuse by adolescents. These fears have been somewhat discounted in recent long-term research by Barkley, Fischer, Fletcher and Smallish (2003; as well as Greenhill & Setterberg, 1993; Klein & Mannuzza, 2002). Barkley et al.'s research has indicated that stimulant treatment in childhood or adolescence is not significantly associated with any form of drug use in young adults. Rather, according to Wilens et al. (2003), stimulant therapy for AD/HD reduced the risk of subsequent drug and alcohol use disorders. Recent research with adolescent males by Molina and Pelham (2003) confirmed Wilens et al.'s findings with regard to alcohol, cigarettes and marijuana, but noted that 20.4% of adolescent males with childhood diagnosed AD/HD were more likely than those without AD/HD (7%) to have used one illicit drug other than marijuana. It should be noted, however, that although Molina and Pelham stated that the adolescents received clinical treatment they did not state the form of treatment received. (Whether treatment effectiveness related to subsequent substance use was studied is not known). Barkley et al.'s (2003) research also identified instances of illicit (non-marijuana) drug abuse in adulthood for those diagnosed with AD/HD in childhood. Barkley et al., however, did establish that the adolescent or child with AD/HD being treated with stimulant medication who was most at risk of cocaine use in adulthood was one with severe current CD symptoms. Severe CD symptoms comorbid with AD/HD was a previously well-established risk factor for substance use and abuse for those with AD/HD-CT and AD/HD-HI (Barkley et al., 2003).

The issue of whether Australian children are being over prescribed or under treated with stimulant medication has been at the forefront of media reporting in the 21st century. Sawyer, Rey, et al. (2002) undertook the first Australia-wide study examining the prevalence of psychotropic medication used by children and adolescents. The findings of Sawyer, Rey et al.'s research indicated that males were more likely to be taking stimulants than females. The proportion of children taking stimulants in Australia (12.6%) was similar to that identified in a study by Jensen, Kettle and Roper, et al. (12%) in the USA in 1999 (Sawyer, Rey et al., 2002), but considerably less than the 72% reported by Angold, Erkanli, Egger, and Costello (2000) in another USA study. In WA 4.2 % of children under 18 were prescribed stimulant medication with the majority of these young people being treated for AD/HD (The Office of Mental Health Department of Health Government of Western Australia, 2002). The National Health and Medical Research Council (National Institute for Mental Health (NIMH) Office of Communications and Public Liaison, 2002) stated, however, that medication prescribing rates in Australia were less than one per cent of school-aged children. The NIMH noted, however, that there was wide disparity between the States and Territories in Australia in stimulant medication prescribing levels. According to Sparke (2000), WA had the highest rate of prescribing of all the States and Territories. Nonetheless, according to Prosser (1997), growth in stimulant medication prescriptions dispensed by pharmacies in Australia from 1990 to 1997 was similar to that in the USA for the same period. In Australia whether the rate of prescribing was based on the West Australia figures or those of the NIMH the prescribing rate was still less than or in line with the estimated prevalence of AD/HD of 3%-5% noted by Barkley (1998), Prosser (1997) and others. Sparke (2000) suggested that the higher prescription rates in WA than other States and Territories reflected a better understanding of AD/HD among practitioners in that State. This view was discounted by Swan, cited by Mackey and Kopras in a document produced by the Federal Electorate (2001), who argued that:

...as soon as you see variations like that in medicine and health, it's usually the fact that there's non-evidence-based treatment going on, that there's opinion-based treatment going on rather than evidence-based treatment going on. (p. 5)

Nonetheless, despite these not inconsiderable concerns raised with the use of stimulant medication and the challenges engendered by adverse side effects, there is greater parental and teacher acceptance of stimulant medication in the treatment of AD/HD (Divoky, 1989; Garland, 1998). As has been discussed, research indicates that the role of stimulant medication is to improve cognition, behavioural inhibition, and self-regulation and thereby improve social and educational outcomes (Barkley, 2001c; Rapport & Kelly, 1993; Schubiner, 1998; Tannock, Schachar et al., 1995). According to Greenhill et al. (1999), although stimulant medication leads to short-term improvement in academic and behavioural levels, this improvement can only be maintained long-term if stimulant medication treatment is continued over time.

Discussion: The Social Perceptions relating to AD/HD.

Social perceptions of AD/HD appear to have been primarily driven by the media. The media has focussed on and sensationalised stimulant medication usage for those with AD/HD. Research has disproved the media 'theories'. According to Barkley et al. (2003) and others, stimulant medication usage does not necessarily lead to substance abuse in adulthood. Moreover, Wilens et al. (2003) suggests that where AD/HD symptoms are effectively managed there is a reduced risk for substance abuse in young people. Parents and teachers are now beginning to accept that stimulant medication improves cognition, behavioural inhibition and self-regulation so that for those with AD/HD social and educational outcomes are improved.

The AD/HD Consensus Statement

The review of AD/HD presented in the second section of chapter two indicates that there is a tremendous body of research associated with this disorder. As the International Consensus Statement on AD/HD (Barkley, Cook, et al., 2002, p.89) stated, many individuals have become familiar with the disorder and have "dedicated scientific studies if not entire careers" to it. Nevertheless, despite the plethora of valid information, reports in the media and general public perception continue to suggest, "ADHD is a myth, fraud, or an innocuous condition that is not valid or real" (Barkley, Cook, et al., 2002, p. 90). The result for individuals with symptoms of AD/HD is a reluctance or failure to seek treatment and increased levels of stress and frustration (Barkley, Cook, et al., 2002). To overcome many of these issues an independent consortium of leading scientists issued an International Consensus Statement on

AD/HD in January 2002 concerning the status of the disorder (Barkley, Cook, et al., 2002). The aim of the consensus document is to be a valid source of information relating to a significant disorder (Barkley, Cook, et al., 2002). It is their stated opinion that the media can help to redress the misconceptions promulgated about AD/HD:

It can do so by portraying ADHD and the science about it as accurately and responsibly as possible while not purveying the propaganda of social critics and fringe doctors whose political agenda would have the public believe there is no real disorder here. ... ADHD should be depicted in the media as realistically and accurately as it is depicted in science – as a valid disorder having varied and substantial adverse impact on those who may suffer from it through no fault of their own or their parents and teachers. (Barkley, Cook, et al., 2002, p. 90-91)

Chapter Two: Summary

Initially, this background chapter discussed research into the period of life referred to as adolescence. Research in this area of adolescence, despite recent developments in research into the sociology of childhood, remains wrapped in the fabric of anthropology, sociology and psychology. These three domains (as well as developmental psychology) are the dominant themes that guide current research into adolescence and adolescent development. Adolescence presently, is not seen from the adolescent viewpoint but from the perspective of their parents and other adults. The adolescent voice is rarely if ever heard. Their voice remains mute and they themselves are marginalised by society as beings in transition from childhood to adulthood, not as interactive agents who with the adults in their lives can learn to direct their lives and take responsibility for themselves.

Socialisation theory, sickness and mental illness theories, the medical model of health and normality and deviance theories continue to direct the way in which society constructs the social environment. Those who do not conform to social mores, values, expectations and conventions such as those with AD/HD, are marginalised and stigmatised.

In line with grounded theory tradition, however, theories that encapsulate sociological, anthropological or psychological discourses of adolescents will only earn a place or be influential in my research if the data analysis dictates that their inclusion is appropriate.

In research such as mine that aims to uncover the experience of a group of adolescents with AD/HD, understanding the culture of the group is essential. It is my contention that unless I develop knowledge about the culture of the adolescent participants in this research, theory about how this group of adolescents with AD/HD manage their lives cannot emerge. The story that emerges in later chapters is not my view of how the participants manage their lives but the participants' own unique perspective that emerged from the data. Understanding how society is constructed and the culture of the adolescents, from their viewpoint as opposed to that of the adults in their world is, therefore, important.

Second, this background chapter presents an overview of AD/HD, its diagnosis and comorbid disorders, stimulant medication usage and the social perceptions of the disorder. Low self-esteem and the possible outcomes such as suicide were also addressed in this section. According to Barkley, Cook, et al. (2002) and others, AD/HD has been recognised in its various forms for over a century. It is one of the most carefully researched mental disorders of the modern era. The body of knowledge has increased with contemporary research particularly that using genetic imaging, neurochemistry, neuropsychological and biological data to provide information on the disorder. Nonetheless, according to Barkley, Cook, et al. (2002), despite the plethora of valid scientific research, AD/HD is still mythologised by the media and in the public perception. Research, for the most part, is based on adult perceptions rather than the views of those who were diagnosed with the disorder. The voice of the adolescent with AD/HD is rarely heard.

Research has demonstrated that individuals with AD/HD have serious deficiencies in a set of psychological abilities (executive functions) and are deficit in behavioural response inhibition and the ability to sustain attention (Barkley, 1997a; 1997b; 1997c; 2000; Barkley et al., 1997). It is these deficiencies that pose the most serious problem for those with the disorder. Adolescents experience impaired social relations, poor education outcomes, problems with family function, low self-esteem and difficulty adhering to social rules, norms and laws (Barkley, Cook, et al., 2002 and

others). Those with AD/HD are more likely than those without to drop out of school, have few or no friends, to engage in antisocial activities. In adolescence those with AD/HD are more prone to risk-taking behaviour than their peers without (Barkley, 1998; Woodward et al., 2000). Some individuals with the disorder who experience low self-esteem have recourse to self-harm. Society's widespread fear of the disorder fuelled by media reports of stimulant medications, the levels at which it is prescribed and its association with the unproven likelihood of drug abuse (Barkley et al., 2003; Wilens et al., 2003 and others) impact seriously on those with the disorder.

Many children with AD/HD and their families experience social rejection and are blamed for behaviours deemed inappropriate. The general public and the media still tend to assume that it is a 'myth'. A Consensus Statement issued in 2002 by a large body of leading scientists who are involved in the field of research sought to redress the many problems experienced by those with AD/HD. This Consensus Statement has endeavoured to dispel myth and rumour that surrounds the disorder and ask that those with AD/HD and their families be treated with consideration.

This background chapter demonstrates that adolescence and the experience of adolescents with AD/HD is for the most part, viewed from the perception of parents, teachers and medical practitioners. The adolescent perspective relating to the adolescent stage of life as well as the experience of the adolescent with AD/HD with regard to their social environment, their disorder and stimulant medication is rarely, if ever, investigated. In other words, both these areas of adolescent research are predominantly adult-centric with very little recourse to adolescent centred opinions about adolescence or AD/HD in adolescence. The paucity of research from the perspective of adolescents with AD/HD demonstrates the significance of my research.

Chapter three will now present the guiding principles framing my research from the qualitative research perspective. Chapter three also presents some of the criteria that will be used to validate this research and the position of the researcher within this study.

CHAPTER THREE

Guiding Principles Framing the Study

Introduction

The significance of my research lies not within the data per se, but in the meaning that is made of the data. To be of value its scientific criteria, i.e., its 'trustworthiness' (generalisability, reproducibility, precision, rigour and verification), must be established (Chalmers, 1998; A.L. Strauss & Corbin, 1990). In the opinion of Piantanida and Garman (1999), for 'trustworthiness' to be demonstrated it is necessary for the reader to be able to audit the events, influences and actions within the research and to be able to observe the researcher's position. With these thoughts in mind, chapter three outlines the thought processes and impelling forces that shaped the study. These processes and forces will be presented not merely from the position of the practical constraints that governed the study but also from the earnest beliefs and understandings that have guided the researcher in this and other research in the field of AD/HD.

Chapter three intends to develop the framework for my research. Initially, it will familiarise the reader with the driving forces behind my research (some of which were discussed in chapter two), including the practical experience gained by the researcher while working in the field of AD/HD previous to this current study. Subsequently, the intention is to furnish the reader with an understanding of where the researcher and the research are located within the field of qualitative inquiry from the perspective of the inquiry and the interpretive paradigm and symbolic interactionism

that underpin my research. The values and ethics that influenced my research and the criteria that became powerful tools in the shaping of my research will also be considered.

Research Procedures and the Influence of Prior Experience

The research procedure or method that is chosen by a researcher may often be an unconscious decision. Research procedure tends to originate from the researcher's methodological knowledge rather than being guided solely by the problem to be studied (Eisner & Peshkin, 1990; Evans, 1995). As Eisner and Peshkin indicate, "Few of us seek problems we have no skill in addressing" (1990, p. 9). The choice of method is also governed by the way in which the researcher views the world. The set of learned 'norms' that define acceptable scholarship for that individual researcher also has a bearing on the method selected (Eisner & Peshkin, 1990). Researchers, therefore, are not detached from the research, but bring to the research their own experience in order to identify problems and investigate them. This view is compatible with my own understanding of how I identified the focus of my research and the procedure adopted.

My experience in the field of AD/HD comes from being both a tutor in special education and a parent of children with disorders, including those who have AD/HD. In the course of tutoring, parenting and research (Carragher, 1997; 1999) I became aware that:

- Families and young people with AD/HD experience many challenges and difficulties, not the least of which are the constraints brought about through the social perception of the disorder which is often contrary to the individual's own perception of themselves and their AD/HD diagnosis;
- Literature pertaining to AD/HD made scant reference to the unique perceptions of those with the disorder, particularly adolescents. Moreover, the majority of the literature did not appear to reflect the social experience encountered by adolescents relating to their diagnosis and stimulant medication usage;

- Received data and literature from which the social construction of the adolescent stage of life was generated would appear to come not from research data derived from adolescents' themselves but was informed by the adult perspective of adolescence;
- That the 'voice' of adolescents and in particular those with AD/HD is rarely heard or listened to.

A further source of data was unique to this researcher. During the time my research was undertaken I was employed in the field of education working with schools, general practitioners and allied health professionals to assist schools and families with children at these schools with chronic disorders that impact on the child's home, school and academic outcomes. It is my opinion that this work enhanced my understanding of the experiences of not only those with AD/HD, but also those with other disorders.

The following poem quoted by Robin (1998) is written by an adolescent who had recently been diagnosed with AD/HD and embodies much of what I have come to experience when talking with those with AD/HD:

"Trapped"
by Charlotte Booth
I feel trapped
like I'm in a cage
screaming
screaming
trapped
trapped.

My heart is confused
I am changing
feelings changing
all new things
coming
coming at
me

I feel safe
in the cage
but
trapped
while
safe

Life is different
I am different
HELP (p. 423)

My research experience has been in the field of qualitative study. The research approach that dominates research about AD/HD is largely quantitative. The research perspective for the adolescent period of life though qualitative was and is largely informed by adult perspectives of adolescence and tends to ignore the perspective of adolescents themselves. Both these research approaches tend to narrow the research perspectives of adolescence and particularly AD/HD in adolescence. This knowledge reinforced my position that my research should seek to address the paucity of research focussing on the unique experience of adolescents with AD/HD and that a qualitative approach was required. I had experienced the capacity of qualitative methods for capturing human perspectives and I believed that such a study would provide more depth of information and personal perspective. Literature associated with AD/HD, for example Barkley (1998); Hazell (1997a; 2000); Prosser (1998; 2000); Robin (1998) and Tannock, Ickowicz and Schachar (1995) and the discourse on the rights of the individual such as those of Ballard (1999); Oliver (1996); Slee (1996); A.B. Smith, Taylor, et al. (2000) and Woodhead and Faulkner (2001) also indicated that there was support for a qualitative approach.

The social experience of adolescents with AD/HD and how they manage their lives thus became the focus of my research. The research framework was to be a qualitative study set in the grounded theory tradition. I wanted to find out what positive and negative experiences, thoughts and opinions the adolescents with AD/HD had with regard to their disorder, their use of stimulant medication and their social experience. I wanted to know how the adolescents with AD/HD perceived they managed their lives and what contributed to, or created these perceptions. To accomplish this required that I discover what was happening that made the adolescents feel comfortable or less than comfortable about how they managed their lives. In order to determine the views of adolescents I had to talk with them but more importantly listen to them. As Hughes (1988) affirmed:

The most obvious advantage of interviewing a child is that the child is the expert (the only expert) on his feelings, perceptions, and thoughts.

...If an adult wants to know what or how the child is feeling or thinking, the adult must ask the child. (p. 91)

The Researcher as Instrument of Inquiry

The aim of my research was to generate understandings and insights into a particular area of the complex phenomenon identified as AD/HD. Although my research endeavours to present the unique world of the adolescent with AD/HD from their own perspective and experience the outcomes in my research must and always will, remain my interpretation of their views.

My research made use of a variety of techniques (to be outlined in chapter four) to gather information about the phenomenon under study but these were only ancillary tools for research set within the inquiry tradition. At the heart of the inquiry was the researcher. Not, from the "traditional stance of a detached and neutral observer"... but as a receptive mind ... "with the capacity for encountering, listening, understanding and thus 'experiencing' the phenomenon under investigation" (Piantanida & Garman, 1999, p. 138). In Eisner's (1990) opinion:

The self is the instrument that engages the situation and makes sense of it. It is the ability to see and interpret significant aspects. It is this characteristic that provides unique, personal insight into the experience under study. (p. 33)

In order to develop 'self as instrument' I adopted the suggestions of Piantanida and Garman (1999) in their book *The Qualitative Dissertation* and Professor Vera Irurita a leading researcher in the field of grounded theory, by commencing with a self-interview. This self-interview demonstrated to me that I had several assumptions relating to both adolescence as a stage of life and those with AD/HD, for instance my adult concepts relating to the use of illicit drugs in adolescence tended to direct my thinking on this subject. I, therefore, had to question myself at all times about whose view I was presenting, theirs or mine, particularly when interview data contained reference to illicit drugs. As the intention of this self-interview was to establish in my own mind how my personal experience impacted on my thinking it proved to be of benefit. I was now aware of my own shortcomings and tried to redirect my stance in

order that my research moved away from my own personal views to a more deliberative posture of inquiry. Nonetheless I am aware and acknowledge that I bring to my research a certain level of bias. As Oakley (1981) argued, it is important to realise that:

... the mythology of 'hygienic' research with its accompanying mystification of the researcher and researched as objective instruments of data collection be replaced by the recognition that personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others in their lives. (p. 58)

In order to reveal the unique perspectives of the adolescents with AD/HD I, as researcher, remained involved with the participants for a considerable period of time (in all eighteen months). During this time I developed the knowledge, skills and trust that allowed me to gain a greater depth of understanding of their perceptions about how they manage their lives in various situations. At the same time I had to ensure that the culture of the group, that was redolent of meaning for the participants, was captured so as to achieve as complete an understanding of their perspective as possible.

The commencement of chapter three referred to the need for research to hear and listen to the voice of the 'other' in order to understand how others feel about issues. Within the data collection and analysis phase resolving the issue of how to uncover and present the participants' account of their selves as their voice, while acknowledging that it was my interpretation, engendered problems. It became, as Woods (1992) had previously argued, a delicate balancing act between presenting their voice from the perspective of the adolescent (i.e., their cultural perspective), while at the same time maintaining sociological distance and being aware of isolating my own cultural framework. In order to accomplish this and to understand the adolescents' perspectives entailed me putting myself (as far as possible) in their situation in order to see the world as they saw it to define how they saw situations. I did not achieve this by "going native" (Woods, 1992. P. 355), but rather by maintaining a delicate balance between ethically correct distance and achieving a complete understanding of participant's perspectives. In the words of Thomas (1928),

(cited in Woods, 1992, p. 352), "If me [*sic*] define situations as real, they are real in their consequences". This is because each individual reacts to symbols (objects, people, experiences) in the light of the meanings these symbols have for them. They do not respond to objective reality or how others perceive the symbols but rather, to how they interpret them.

Accepting that adolescents with AD/HD, as with their adolescent peers, were not a homogeneous group, my research focused on how ten adolescents with AD/HD individually adapted themselves to manage their lives in multiple settings.

The role of the researcher is, as Morris (1989; 1992) argued and as I perceive it, to draw together the main themes from all the stories furnished by the adolescent participants and present them so that others may view them, not as the act of a ventriloquist, but as an account, albeit an interactive one, of the unique world of adolescents with AD/HD.

Identification of the Research Paradigm

Qualitative Inquiry in the Context of this Study

The way in which a researcher approaches and studies a problem is influenced first, by the researcher's methodological knowledge and second by the constraints and complexities of applying qualitative research to a problem (Denzin & Lincoln, 1994). Drawing upon Janesick's (Denzin & Lincoln, 1998a) analogy, research design parallels a choreographed dance production "with distinct phases: warming up, exercises and design decisions, cooling down, interpretation, evaluation, and criticism" (Denzin & Lincoln, 1998a, p. xiii). Qualitative research is shaped through interactive interpretation and by its very nature necessitates very careful choreography if it is to convey to the reader an in-depth understanding of the phenomenon under review.

According to Piantanida and Garman (1999), qualitative inquiry is an inquiry that explores the broad understanding of human conversation and narrative and examines essential attributes within human experience. The very strength of the qualitative research method is that:

Qualitative researchers self-consciously draw upon their own experiences as a resource in their inquiries....They seek strategies of empirical inquiry that will allow them to make connections among lived experience, larger social and cultural structures, and the here and now. (Denzin & Lincoln, 1998, p. 35)

Qualitative methods, unlike quantitative methods, are not constrained by the need to employ standardisations that limit the understanding of people's perspectives and experiences to responses to questions in carefully constructed research instruments that are measured numerically. In qualitative inquiry "the researcher is the instrument" (Patton, 1990, p. 14) and, therefore, qualitative research by its very nature cannot be a detached process. Rather it must be a cooperative effort between two people, the researcher and the researchee where the researcher is impelled by their obligation to give voice to the stories of others - albeit in the context of researcher's own inevitable interpretation (Denzin & Lincoln, 1998a).

The imperative of my research, as a qualitative inquiry, is as a "commitment to understanding the world as it is, to be true to complexities and multiple perspectives as they emerge and to be balanced in reporting both confirming and disconfirming evidence" (Patton, 1990, p. 55). Consequently, while presenting a window on life mirroring as it does social experience, qualitative inquiry also serves to intrinsically influence the shape of the phenomenon it examines (Denzin & Lincoln, 1998a, 1994). It is an interactive process that "is shaped by [the researcher's] personal history, biography, gender, social class, race and ethnicity [as well as] those of the people in the setting" (Denzin & Lincoln, 1994, p. 3).

Qualitative methods in themselves are only the starting point for research. In Guba's (1990, p. 22) words "the term *qualitative* is a methods-level term" where the structure and organisation of qualitative research stems from paradigm. It is paradigm that structures disciplined inquiry through criteria, assumptions and methodological practices that form the framework for research. In the opinion of Denzin and Lincoln (1998a), the type of knowledge produced reflects more the fundamental paradigms that underpin the research than actual method utilised. As McKenzie (2001) observed, paradigm is of higher order concern for researchers than method, as choice of method is guided by research paradigm.

Paradigms

According to Guba (1990), the research paradigms, or basic belief systems that guide disciplined inquiry depend on the way in which advocates respond to three basic questions:

(1) *Ontological*: What is the nature of the "knowable"? Or, what is the nature of "reality"?

(2) *Epistemological*: What is the nature of the relationship between the knower (the inquirer) and the known (or knowable)?

(3) *Methodological*: How should the inquirer go about finding out knowledge? (p. 18)

In the opinion of Guba (1990), the paradigm associated with these questions is identified by the terms post-positivism, critical theory and constructivism. From the post-positive position research is judged using the principles of objectivity, validity and reliability, whilst the critical theorist, on the other hand, is more ideologically oriented towards the foundations of critical theory stemming from Marxism. The critical theorist tends to direct research towards social, historical, political, gender and(or) economic forces (Cheek et al., 1996). Constructivists are distinguished by their relativist belief that the social world is constructed from within the realm of individual consciousness and subjectivity based on the beliefs and understandings of participants, as opposed to that of the observers of the action (Crotty, 1998; Denzin & Lincoln, 2000; Guba, 1990). While Guba distinguished between ontology and epistemology in order to outline these paradigms for consideration, he argued that in constructivism "the ontology/epistemology distinction is obliterated" because "reality or what can be known (ontology) and the relationship between the knower and the known (epistemology) are inextricably linked" (Guba, 1990, p. 27). More specifically, Guba maintained that "inquirer and inquired into are fused into a single (monistic) entity" (Guba, 1990, p. 27).

The guiding paradigm for my research is constructivist and is set within the interpretive position. It was interpretivism aligned with the symbolic interactionist

perspective that, therefore, became the tools that contributed to an understanding of human action and which facilitated the development of theory through the grounded theory method of data collection and analysis.

The interpretive paradigm.

The interpretive paradigm, as the underpinning theoretical construct for my research, was crucial to the grounded theory analytical process in order to uncover the unique perceptions of adolescents with AD/HD. The instruments that facilitate understanding of the fundamental realities of the world from the perception of others are interpretive paradigm and symbolic interactionism (Burrell & Morgan, 1979; Crotty, 1998) and their use was, therefore, essential to my research. It is through interpretive inquiry and symbolic interactionism that the adolescents' experiences, opinions, needs and problems related to their disorder, their stimulant medication usage and the impact of these issues on their home, school and social environment could be defined. Interpretivism and symbolic interactionism also allowed for discourse to evolve on how they were able to manage their lives. The understanding that evolved from my research came, therefore, from within the realm of individual consciousness and subjectivity based on the beliefs and understandings of the participants themselves, as opposed to that of the observers of the action - parents, teachers and health professionals.

The importance of the interpretive paradigm in my data analysis was based on the knowledge that AD/HD research to date has been, for the most part, been interpreted from a medical model of health perspective (chapter two). This model had its foundations in structural functionalism, whereas, the interpretive paradigm, as Burrell and Morgan (1979, p. 32) argued, "challenges the validity of the ontological assumptions which underwrite functionalist approaches to sociology". The structures that sustain interpretive theories are underwritten by the notion that beliefs relating to the nature of "*status quo, social order, consensus, social integration and cohesion, solidarity and actuality [their italics]*" (Burrell & Morgan, 1979, p. 31) furnish the rationale for comprehending the subjectively created social world. This is notwithstanding that this perception suggests to some extent, that the interpretive philosophy is implicit rather than explicit in its understanding of 'how the world is' (Crotty, 1998).

The process of establishing a framework from which to undertake my research led me to question my own beliefs with regard to prior knowledge and the effective use of the research process. I aligned myself with the interpretive paradigm and symbolic interactionism as its assumptions matched my own that "requires each of us to come to terms with a union of moral and cognitive concerns in our own and others lived experience" (Schwandt, 1996, p. 81). For example: the interpretive paradigm, with its roots in the concepts of Max Weber (1864-1920) derives its understanding from the actions and interactions of human beings in which reality is individually constructed from individual constructions. Symbolic interactionism, with which the interpretive paradigm is aligned, is according to Blumer (1969, p. 1) "a distinctive approach to the study of human group life and human conduct" that addresses the methodological imperatives of interaction amongst people.

Symbolic Interactionism: Its Contribution to the Study

Symbolic interactionism has its origins in the intellectual work of a notable body of American researchers of the Chicago School (USA) foremost of whom was George Herbert Mead (1863-1931). It was Mead who was responsible for constructing a theory that elaborated on the role of symbols in human interaction as they relate to the nature of mind, self and society (Rosenberg & Turner, 1981; Woods, 1992). It was, however, Blumer who according to Woods (1992), first adopted the phrase symbolic interactionism. Glaser and Strauss (1967) with their grounded theory method adopted the principles of what was to become symbolic interactionism. According to Denzin & Lincoln (2000) and Woods (1992), as a constructivist interpretive perspective, symbolic interactionism informs grounded theory procedures and furnishes research with a wealth of empirical data.

The fundamentalist premises that are symbolic interactionism are:

- (1) human beings act toward things on the basis of the meanings that the things have for them,
- (2) this attribution of meaning to objects through symbols is a continuous process, and

(3) meaning attribution is a product of social interaction in human society. (Woods, 1992, p. 338)

The position of symbolic interactionism i.e., the way in which individuals view things and the way in which they act towards or interpret the meaning of things, is central to understanding the actions and interactions of individuals. Symbolic interactionism recognises that the process of social interaction is not merely a demonstration of the process of human behaviour, but that rather social interactions between individuals in society depend on how each of the parties accounts for the other's actions and reactions. How they themselves direct their own actions to take account of the interaction of the other and the situation within which they find themselves, is also recognised. The action of an individual, or a group of individuals, is, therefore, determined by the action of others as symbolic meaning (Blumer, 1969). Symbols are "indirect ways of representing physical objects, other people, experiences and even abstract ideas and thoughts" (Hewitt & Hewitt, 1986, p. 9). Interaction, activity and individual conduct, therefore, form part of an ongoing process of "defining to others what to do and interpreting their definitions; through this process people come to fit their activities to one another and to form their own individual conduct" (Blumer, 1969, p. 10). Woods (1992) contended that the self is at the heart of symbolic interactionism.

Self as a concept in symbolic interactionism.

According to Rock's (1979) interpretation of Mead's theory, the self is "the lens through which the social world is refracted. It is the medium which realises the logic of social forms. Fundamentally, however, self emerges from [*his italics*] the forms" (Rock, 1979, p. 146). Mead's theory maintained that every individual "is socially constructed. The 'Me' - the self as constructed view the 'generalised other' - plays a central role in the process" (Crotty, 1998, p. 62) of how an individual manages in their world. According to Blumer (1969), by identifying self as the indicator (director) of the process the individual is allowed to disengage the given self in the situation and to objectify self by giving self meaning or character. As Woods contended, "we can stand outside ourselves and look at ourselves much as we would look at any other object" (1982, p. 123). Or, as Blumer (1969) explained:

Each of us is familiar with actions of this sort in which the human gets angry with himself, rebuffs himself, takes pride in himself, argues with himself, tries to bolster his courage, tells himself he should 'do this' or 'do that', sets goals for himself, makes compromises with himself, and plans what he is going to do. (p. 79)

In consequence, the individual is able to construct the meaning and character of objects on the basis of ongoing activity rather than be subjected to "an environment of pre-existing objects which play upon him [*sic*] and call forth his behavior" (Blumer, 1969, p. 80). Nevertheless, according to both Blumer (1969) and Woods (1992), the key feature of Mead's argument was that for behaviour to become interactive in the social sense the individual must first regard the situation imaginatively through the eyes of others and interpret the situation from that position:

Just as objects can be interpreted differently on different occasions or by different people (a ruler, for example, can be a measuring instrument, a weapon, an indicator, a musical instrument, an aid to reading and writing, and so on), so situations must be interpreted. (Woods, 1992, p. 344)

This self-indicating process is, according to Blumer (1969), a step-by-step process and not a response to outside environmental pressures, motives, attitudes, ideas and stimuli. It is an internalising thought process of interpretation, construction and direction of conscious action/reaction "to take account of the demands, the expectations, the prohibitions and the threats as they may arise" (Blumer, p. 81) in any given situation. According to Blumer, it was Mead's contention that construction of meaning interaction is the outcome of an individual's ability to acquire the role of other to see oneself as that other and to interpret self from that stance. This shared understanding of the interaction and action between self and other is social action and not merely behavioural response. While this internalisation and sharing of symbolic meaning may be non-verbal, such as a frown that indicates displeasure at an action, it is important that meaning is shared verbally and expressed through language. The use of language is an important part of the internalisation process for it allows the stimulation of reflective thought (Woods, 1992). The individual is then able to reflect

not only on the process but is also able to see self as the object, and through the internalisation of language interpret self as other thus guiding action towards others from the perspective of self (Wood, 1982). In this way interaction between individuals is socially instigated. Socialisation and social systems are the processes that guide action and interaction in society.

Self and socialisation in symbolic interactionism.

The socialisation process that determines the adult self commences in childhood through the processes of play and game participation. It is through the acquisition of language that a child comes to realise that the defining of objects by names shares meaning with others. In the early play stage children relate to each other solely as individuals. It is only when the game stage is reached that the child, facilitated by rules of the game, is able to participate in group activity with the knowledge that shared understanding allows them to coordinate themselves while simultaneously adopting role of the other participants in the game. As a consequence, each individual is able to see themselves as others see them, not just in the context of behaviour but as members of a team, group or a society where norms, values and beliefs also serve to guide action and interaction (Woods, 1992). According to Woods, as an individual matures so their own experiences invest situations with differing meanings to be accounted for and taken note of for future action and interaction. Mead (1934) referred to this as "the generalized other;" the concept is crucial to his interpretation of the relationship between self and society:

It is in the form of the generalized other that the social process influences the behavior of the individuals involved in it and carrying it on, that is, that the community exercises control over the conduct of its individual members; for it is in this form that the social process or community enters as a determining factor into the individual's thinking. (p. 155)

It is Woods' (1992) contention that this statement by Mead does not imply that society controls the individual; rather it is social organisation that provides guiding principles for the individual to act upon. According to Blumer (1962, p. 189-190), it is structural features such as 'social class', which set conditions for the action of self

rather than action of self being a response to social mores. Nonetheless it is social systems that furnish the individual with guiding principles upon which to act, the "generalized norms, values and beliefs in terms of a team, or a subcultural group, or a society" (Woods, 1992, p. 344). According to Woods (1992), these principles that shape social organisation may be understood as "fixed sets of symbols which people use in interpreting their situations" (Blumer, 1962, p. 189-190).

As societies, particularly contemporary societies, are becoming more complex there is a need for flexibility in social organisation so that the individual may define interaction in context, not just of each situation but also from the perspective of self as an interpretive interactive participant. With increasing complexity, social reality and social expectations have become multifaceted and many layered, with every new layer bringing with it a different understanding of the whole; hence, in Blumer's (1976, p. 15) words, it is like "lifting veils".

The major socialising entities in Australia today are family, education, religion, economy, government and leisure (Grbich, 1996). Each of these entities vary in the degree of impact they have on patterns of social behaviour entrenched in each individual, insofar as each of these entities is responsible for differing and specific guiding aspects of the socialisation process within each individual (Grbich, 1996; Harris, 1969; Hunt, 1978). This statement may at first sight appear to ignore the self as an individual within society; it is not my intention, however, to do so. Rather it acknowledges, as Blumer (1969) contended, that social systems and the patterns of behaviour that guide the social action of others, may be tempered by the interpretive behaviour and the construction of action of those who form the group that is the influencing socialising entity. Thus social systems form part of the ongoing process of mediated interpretation of situations.

Chapter two established that, in sociological terms, the major socialising entities in Australia today were inclined to view society in terms of:

- structure or organisation and their role in determining social action, i.e., culture, norms, values, social stratification, status positions, etc. (Grbich, 1996; Harris, 1969; Hunt, 1978);
- social organisation in terms of function;

- "societal organization as a system seeking equilibrium, and
- the forces of change that play upon organisation". (Blumer, 1969, p. 87)

As chapter two disclosed, despite changing views, advocated by A.B. Smith, Taylor, et al. (2000) and others, these sociological axioms are the ones that guide social systems and patterns of behaviour which themselves guide the social action of others. It was Blumer's (1962; 1969) argument, however, that "these various lines of sociological perspective and interest...[which are today as strongly entrenched as they were then]...leap over the acting units of a society and bypass the interpretive process by which such acting units build up their actions" (Blumer, 1969, p. 87). The application of the symbolic interactionist perspective for my data analysis, therefore, permits social systems to be seen and understood as the framework inside which individual units develop their actions, rather than social systems i.e., culture, social roles and social strata, determining social action. In this way the shared ideas, beliefs, assumptions, values, expectations and appropriate patterns of behaviour of the socialising agencies that form the culture of a group (Craig, 1996) may be viewed not as a prescriptive list of behaviours, but as an abstract model offering general guidance. For according to the symbolic interactionism perspective the individual is not responding directionally to social conditioning but actively adapting to the circumstances in which they find themselves.

The Grounded Theory Approach

While interpretivism and symbolic interactionism underpin my research, they have their limitations. For instance:

...symbolic interactionist studies produce a wealth of empirical research, mainly descriptive, with some "interesting theoretical ideas" but not much "culmination of theoretical knowledge. (Woods, 1992, p. 392)

The use of the grounded theory method as the basis for data collection and analysis, therefore, becomes appropriate for my research as the grounded theory method transcends existent theories and preconceived conceptual frameworks in its search for new understandings of social processes in natural settings (Stern, Allen, & Moxley, 1982). The intention of my grounded theory research is to build upon and extend current AD/HD research by focussing on context, lived experience and patterns of experience of adolescents in WA with AD/HD. As Hutchinson (1988) observes:

Grounded theories are guided by the assumption that people do, in fact, have patterns of experience. They order and make sense of their environment, although their world may appear disordered or nonsensical to the observer. The order or pattern derives from their shared social and symbolic interactions. Reality is a social construct...
(p. 125)

A detailed discussion of the grounded theory method will be presented in chapter four.

Values and Ethics within the Research Process

Research is not Value Free

Part of the purpose of chapter three is to disclose the values and beliefs that influenced my research. Interactive interpretive research can never, according to Lincoln and Guba (1985) and Woods (1992), be value-free but is value-mediated embodying as it does the researcher's own underlying value system. This is contrary to the positivist position that claims that values are distinct from facts (Lincoln & Guba, 1985). It is the positivistic argument that the choice of methodological inquiry sanctions eliminating the former values from the research while focussing on the facts. In the opinion of Lincoln and Guba (1985), however:

... epistemologists line up heavily in favor [sic] of the proposition that "facts" are theory-laden; that it is impossible even to recognise a "fact" except within the framework of some theory. But theories are themselves constructions - some out of whole cloth - and they rest on

their own axioms and assumptions, which are also values in our sense of the term....If theories are value-determined and facts are theory laden, then facts must also be value-determined. (p. 182)

Constructivism replaces positivistic criteria of internal or external validity because reality is, in itself, constructed in the eyes of the beholder (Woods, 1992). The production of social knowledge is openly ideological in that the researcher's values "not only implicitly affect aspects of the inquiry process but may in fact be the central driving force in the work" (Lincoln & Guba, 1985, p. 175).

Prior to commencing this thesis I have been involved both in my work in schools and in my own research with families whose children and/or adolescents have been diagnosed with AD/HD. In my work and my own family I witnessed at first hand the harm that emanated from the stigma associated with the diagnosis. I am also of the view that using labels to categorise people is inappropriate. It is my belief that AD/HD is a real condition that should be acknowledged and recognised within the community.

Embodied within the thought that research cannot be value free and in light of the knowledge that the researcher is an interactive participant in interpretive research, ethical considerations about how knowledge is created and shared and how particular phenomena are studied and perceived became paramount. As (Denzin & Lincoln, 1994, p. 14) explained "the age of value-free inquiry for the human disciplines is over, and researchers now struggle to develop situation and transsituational [*sic*] ethics that apply to any given research act".

Ethical Considerations

There are ethical principles which guide research regardless of research paradigm. Prior to the commencement of my research, permission to undertake the study was sought from the Ethics Committee of Edith Cowan University. The principles laid down by this University and other research bodies typically relate to methods for contacting and inviting individuals to participate in research projects. These invitations must clearly outline the research topic and the amount and type of participation required. Participants must be assured of complete confidentiality of information and comprehend that they are invited to participate (which means they

have freedom to withdraw from the research at any time). Inherent within the contact and permission process for research is the knowledge that participants should be able to both understand and agree to the terms and conditions under which they participate. The overarching ethical principle governing research is that researchers will do no harm (McKenzie, 2001). Even when following implicitly predetermined ethical principles, however, the researcher must remain ethically vigilant throughout the study. For, in the words of Patton (1990):

Interviews are interventions. They affect people. A good interview lays open thoughts, feelings, knowledge, and experience not only to the interviewer but also to the interviewee. The process of being taken through a directed reflective process affects the persons being interviewed and leaves them knowing things about themselves that they didn't know - or at least were not aware of - before the interview. Two hours or more of thoughtfully reflecting on an experience, a program, or one's life can be change-inducing. (p. 353-354)

This, therefore, becomes the dilemma of the interactive interviewer. In the process of developing rapport and asking people to talk about themselves the interview might open Pandora's Box. Being cognisant of this is an imperative of interactive research. Particularly, as Lincoln and Guba (1985) remarked, when the emphasis of this mode of inquiry is for face-to-face interaction in which multiple constructed and often conflicting realities are raised then faithfully represented in extensive word-for-word natural language while maintaining privacy and anonymity.

The previously discussed ethical considerations address in general the potential for risks and sensitivities, however, it is up to the researcher to further identify risk specific to their own research. According to Sieber (1993, p. 19) "this means learning to perceive risk factors from the perspective of the persons who will be affected, remembering that not everyone perceives things as the researcher would". Confidentiality and anonymity were cornerstones of my research as they sought to overcome risks that I may encounter. For example, I was aware that those with AD/HD often maintain secrecy about their diagnosis because of the fear of others 'finding out' and being concerned about what would happen to them. As my research was clearly set in the field of AD/HD the involvement of a participant must remain a

secret. Confidentiality and anonymity, therefore, became the most important factors associated with my conversations with the adolescents with AD/HD.

Understanding and responding constructively to the needs and fears of participants is an important part of culturally sensitive research. Cultural sensitivity refers to a researcher's ability to understand and approach the research topic in a way that is commensurate with the conventions of the culture or subculture of the participants and to stay in touch with current public and culturally specific thinking on the topic (whether true or false). It is axiomatic in interactive research that to understand cultural language of the culture being studied - in this case the adolescent culture - it is necessary, therefore, to understand the language of the culture (Patton, 1990) (see chapter two for details). A broad picture of what the West Australian adolescent regards as is important may be found by going to the World Wide Web and connecting to the Youth of Today on <triplej.abc.net.au>.

Acknowledging the potential effects of the research on the participants, with the understanding that it behoves the researcher to do no harm, is an onerous responsibility. The focus of my research brought with it not only this knowledge but also an inherent understanding of responsibility that the interviews or conversations with participants may arouse unpleasant feelings for them or rekindle emotions associated with past events. Where I became aware that a participant was concerned or upset about an issue being discussed I either moved away from the subject and returned to it later, or enquired if the participant wanted to talk about the problem. I gauged my response according to my knowledge of the participant and the strength of their emotion relating to the issue or problem.

As previously discussed my interaction with the research participants with self as instrument involved bringing my own perceptions and interpretation to their words. By identifying and acknowledging my biases and preconceptions I was able to both temper and monitor their influence. By acknowledging this perspective I came to the conviction that my research would legitimately reflect the perceptions of the participants and would be understandable to them, to other people in similar circumstances and to people outside their situation.

Criteria for Judging Qualitative Dissertations

I recognise that in my research trustworthiness (generalisability, reproducibility, precision, rigour and verification) must be established. For me to demonstrate trustworthiness it is necessary for the reader to be able to audit the events, influences and actions within the research and to be able to observe my position within the research. The 'logic of justification' becomes an imperative for researchers as they seek to logically justify the process and procedures inherent within the story portrayed in a study and the reasons behind each move or change of direction as one portrayal progresses to another. The credibility of qualitative inquiry rests on a researcher's ability to lucidly explain the 'logic of justification' (Piantanida & Garman, 1999). To achieve this aim Piantanida and Garman (1999) found the following list of criteria useful in judging the trustworthiness of qualitative study and it is my intention that they become precept for my research:

Integrity (as in architecture). Is the work structurally sound? Does it hang together? Is the research rationale logical, appropriate, and identifiable within an inquiry tradition? Is the proper persona (or voice) used for the author(s) and other participants?

Verité. Does the work ring true? Is it consistent with accepted knowledge in the field? Or, if it departs, does it address why? Does it fit within the discourse in the appropriate literature? Is it intellectually honest and authentic?

Rigor. Is there sufficient depth of intellect, rather than superficial or simplistic reasoning? Are the conclusions carefully crafted from sufficiently thick and rich data? Does the researcher avoid solipsistic reasoning? Was reflection done in a careful/systematic rather than haphazard fashion? Has the analysis/interpretation of the core portrayal been thorough/exhaustive?

Utility. Is the inquiry useful and professionally relevant? Does it make a contribution to a recognized field of study or established bodies of discourse? Does the piece have a clearly recognizable professional and(or) scholarly audience? Is it educative?

Vitality. Is the inquiry important, meaningful and nontrivial? Does it have a sense of vibrancy, intensity, and excitement of discovery? Do metaphors and images communicate powerfully?

Aesthetics. Is it enriching and pleasing to anticipate and experience? Does it give me insight into some universal part of my educational self? Are connections between the particular and the universal revealed in powerful, provocative, evocative, and moving ways? Does the work challenge, disturb, or unsettle? Does it touch the spirit?

Ethics. Is there evidence that privacy and dignity have been afforded all participants? Has the inquiry been conducted in a careful and honest way? Has every effort been made to represent the views of others accurately and in the spirit with which they were shared/intended? Has the researcher recognized and acknowledge his or her own preconceptions/biases/assumptions and considered how these might distort understanding? Does the language of the dissertation adhere to the principles of nondiscrimination? Does the inquiry have an ethical sensibility? (Piantanida & Garman, 1999, p. 147-148)

These criteria established by Piantanida and Garman (1999) will be revisited in chapter eight where my dissertation will be reviewed in light of these criteria.

Chapter Three: Summary

The aim of chapter three has been to explain the framework for my research. The design of my research was influenced by my past experience, the dearth of literature relating to the opinions of adolescents with AD/HD and research discourse, particularly the interpretive paradigm and symbolic interactionism. Chapter three,

therefore, has discussed where and how the researcher is located within the research, as an interactive participant and the ethical principles and criteria that have guided the research⁶.

The theoretical paradigms interpretivism and symbolic interactionism that underpin my research are explained in the context of my research. The interpretive paradigm, as a constructivist perspective, wherein ontology and epistemology are united in the production of knowledge, furnishes my research with an illustration of reality from the standpoint of adolescents with AD/HD. From the symbolic interactionist perspective the adolescent's viewpoint is seen as social construction within the realm of individual consciousness and as a subjective perspective of the beliefs and understandings of the knower and known within the research.

Socialisation, referred to in both chapter two and chapter three, is the social process whereby individuals acquire the knowledge that allows them to interpret, interact and participate in society on an equal footing with others (Grbich, 1996; Harris, 1969; Hunt, 1978). Where the symbolic interaction perspective differs from other sociological constructs is in the acknowledgment of self as the individual who acts on the basis of internalised self-indicating thought and through interactive conversation, not as an organism whose action is determined by factors that impact upon it (Blumer, 1969).

Chapter four will now present a detailed account of the research design and procedures that were employed in my research, followed by an in-depth explanation of the grounded theory methodology.

⁶ The rationale guiding this chapter and the way in which it is constructed came about as a result of a seminar in 2001 at Murdoch University, WA at which Dr. Susan McKenzie (who had recently completed her PhD) was a presenter (2001). It was her discussion on the location of the researcher within the research and the value of a chapter such as this that led me to include it in my dissertation. I would like to thank Dr. McKenzie.

CHAPTER FOUR

Methodology

Introduction

The previous chapter discussed the framing of my research and the nature of qualitative research per se, together with the theoretical constructs that underpin my research - namely the interpretative paradigm and, located within this paradigm, Blumer's symbolic interactionism (1969). My prior experience in the field and my position in the study as researcher and as an interactive participant were also articulated. Chapter three initiated a discussion on the ethical considerations applied and the overall criteria guiding my research. Chapter three also emphasised that doing no harm to the participants was an imperative for my research.

Chapter four will now set out the way in which my research was executed; the methodology, research design and procedures that were followed. The introduction includes an overview of the grounded theory method, my rationale for using the grounded theory method and a detailed account of how the grounded theory data collection and analysis process is employed. The computer software used to support my research analysis is also explained, along with the specific criteria guiding the grounded theory aspect of the research that reveals how issues of 'trustworthiness' are addressed. Finally, the further special considerations and limitations that influenced areas of my research will be referred to. First, however, chapter four will focus on the central research question that directed the study.

Central Research Question

My research, set in the grounded theory tradition, is fundamentally underpinned by the interpretative paradigm and symbolic interactionism which is located within this paradigm. This research approach supports the notion of discovery, oriented towards action, reaction and process. Utilising grounded theory method is consistent with the orientation of the central research question that seeks to explore the world of the participants through their eyes and then identify the basic social processes or structures employed by the participants to organise this world. In grounded theory study the onus is on the researcher to uncover the "patterns, action and interaction" between and among the "actors" (Chalmers, 1998; Strauss & Corbin, 1994). As an inductive and deductive approach to theory construction in which the processes under study are discovered and conceptualised from and grounded in, empirical data, grounded theory includes procedures for developing theory about a central research question generated through investigative guiding questions (Chalmers, 1998).

The orientation of my central research question was influenced by observations made in the early research interviews. Prior to the commencement of data collection the research question had been written thus: in what way do adolescents with AD/HD manage their disorder and treatment regimes when they are allowed to become their own advocate (their own voice) in the design of youth driven individual case conferences? The premiss that directed this initial research question assumed that adolescents with AD/HD would require assistance to develop a strategy or strategies in order to manage their lives. The thinking that directed this first research question was derived from the following:

1. As research documents, adolescents experience significant changes in life course behaviour and attitudes during puberty (Berger, 1988; Bjorklund, 1995; Jaffe, 1998), at the same time adolescents seek to establish their own autonomy.
2. The popular image of adolescence is of an interlude of storm and stress (though this is not strictly accurate), it is also a time of particular challenges both at home and in the school environment. Nonetheless uniquely adolescent studies associated with the adolescent stage of life are rarely undertaken (Bergin, Talley, & Hamer, 2003; Garland, 1998; A.B. Smith, Taylor, et al., 2000 and others).

3. Moreover, as research documents, the adolescent voice in AD/HD research is rarely heard and the adolescents are rarely consulted about their specific opinions, needs and problems. Presently, parents, doctors and teachers tend to direct the way in which the lives of adolescents with AD/HD are managed, citing risk taking behaviour and poor educational and social outcomes as their reason for 'not letting go of the reins'.
4. The individual case conference procedure in which all parties contribute to a 'round table' discussion is an effective vehicle for discovering management strategies in a group discussion. In this situation not only are the parents' opinions sought but also and more significantly, the adolescent voice may be heard and listened to.

It became apparent from early initial data observations that the assumptions directing my initial research question tended to be too presumptive and there was a need for me to re-conceptualise the focus of my research and research question. Taking account of these observations the research question was reframed to clarify the position prior to commencement of the major data-gathering phase. Using early data in this way as a pilot study allowed for the research question to be refined and restated. It was essential, however, that the research question should remain broad enough to satisfy all the questions that derived from the original research question, while at the same time acknowledging the need to realign and widen the focus. According to Glaser (1998) and Strauss and Corbin (1998), this use of early data as a pilot study, is consistent with qualitative research in the grounded theory tradition. This approach sanctions the researcher to capture "all of the variation in the phenomena under study and examine conditions under which the phenomena occurs, as well as conditions under which it varies" (Chenitz & Swanson, 1986, p. 41).

The new research question was now framed from the perspective of the following:

1. That research appertaining to the experience of adolescents with AD/HD relating to their disorder and the use of stimulant medication is, for the most part, based on the adult perception. The adolescent voice is rarely heard.
2. As far as it has been possible to ascertain, no specific long-term qualitative study has been carried out with a group of adolescents in WA diagnosed with AD/HD,

according to two subtypes (with no comorbidities), relating to their opinions and experiences, needs and problems associated with their diagnosis of AD/HD and the use of stimulant medication.

3. A theory has not been constructed as to how a group of adolescents in WA with AD/HD manage their lives.

In my research the grounded theory approach is used to form a theory about the phenomenon outlined in the central research question. The intention is that this theory will explain the social problem encountered by the adolescent participants and the basic social process by which they manage their lives. This theory will also aim to account for the influence of the basic social problem experienced by this group of adolescents with AD/HD in WA and demonstrate how they manage their lives.

The central research question is now stated as follows:

What is the experience of adolescents in WA diagnosed with AD/HD with regards to their diagnosis and the use of medication in the context of their home, school and social environment; in what ways do they manage their lives?

The social experience of adolescents diagnosed with AD/HD and how they manage their lives thus became the focus for my research.

Research Design

The Grounded Theory Method: An Overview

Background.

The grounded theory method originated in the United States of America in the 1960s and was developed by two sociologists, Barney Glaser and Anslem Strauss. They first met when Glaser was invited by Strauss to teach research methodology and work with him on a study entitled *The awareness of dying* at the University of California, San Francisco (Glaser, 1998; Hutchinson, 1988). In Hutchinson's (1988) opinion, they formed a surprising team, coming as they did from different research backgrounds. Glaser's research experience was quantitative, based on the ideologies of Robert K. Merton and Paul Lazarsfeld from whom respectively he learned theory

construction, theoretical coding and inductive quantitative analysis (Glaser, 1998). Strauss, on the other hand, had studied with George Herbert Mead, Herbert Blumer and Everett Hughes in the Chicago tradition with its somewhat "amorphous research methodology" (Hutchinson, 1988, p. 123). When he and Glaser met, Strauss was working with Howie Becker and had received, along with Becker, funding to study dying in hospitals. The results of Glaser and Strauss's collaboration were published in their pioneering book on grounded theory entitled, *The Discovery of Grounded Theory* (Glaser & Strauss, 1967).

The impetus behind Glaser and Strauss's new method, with its rich ethnographic traditions in the Chicago School, came from their desire to challenge the rapid ascendancy of quantitative research which at that time, in their opinion, served to marginalise qualitative studies. According to Glaser, the "Discovery book's attack on theoretical capitalism and its supplementing and supplanting the ruling canons of quantitative research is now history" (Glaser, 1998, p. 32). In Hutchinson's (1988) opinion, the success of Glaser and Strauss was due in part to quantitative research seeking to generate grand theories without seeing fit to test them and that these grand theories related to global concepts that bore little relationship to one another in everyday life. Whereas, grounded theory, with its roots in the pragmatic philosophies of George Herbert Mead, Paul Lazarsfeld and Robert K. Merton as well as Herbert Blumer's symbolic interactionist perspective, sought to bring to research substantive theories that explain a specific area of empirical inquiry (Hutchinson, 1988). According to Strauss and Corbin (1990), the grounded theory method was a "powerful way of interpreting reality, a reality which cannot actually be known but is always interpreted" (p. 22), unlike many formal theories which, in the opinion of Glaser (1978) and also Irurita (1990), were speculative or ungrounded. As Glaser argued, formal theories are the "whims and wisdoms of usually deceased great men, conjecture and assumptions about the "oughts" of life and other extant speculative theory" (1978, p. 123).

Glaser and Strauss's perspective relating to procedures and techniques for grounded theory study developed in the *Discovery* book later diverged and a long running argument ensued. Both scholars continued to develop and teach the grounded theory research method but each did this in their own way. In my research I have

chosen to involve the thinking of both eminent scholars, as well as the thoughts of Juliet Corbin who later came to assist Strauss with his work.

What is the Grounded Theory Method?

The grounded theory method is a systematic, constant comparative process of data collection and analysis. The fundamental strategies of the grounded theory approach are: simultaneous collection and analysis of data; a three stage coding process of open, axial and selective coding; constant comparative methods; theoretical sensitivity and sampling to refine the emergent theoretical notions. Memos and code notes (conceptualisations, interpretations and analysis of ideas generated from the data) are written throughout the research process. In Glaser's words "doing grounded theory is subsequent, sequential, simultaneous, serendipitous and scheduled [but] not in this or any other predetermined order" (1998, p. 15). The significance of the grounded theory method is its emphasis on the researcher going to participants in order to attempt to understand their perspective within a given situation (Hutchinson, 1988). The grounded theory method as an analytical process that is grounded in data moves the research forward "toward the development, refinement and interrelation of concepts" (Denzin & Lincoln, 2000, p. 510) and the emergence of theory.

According to Glaser (1998), grounded theory is both an inductive and deductive approach to theory construction in which carefully grounded deduction from an inducted category or hypotheses directs where to go next for data to compare. As a result all data are able not only to initiate new theory but also to reformulate, refocus and clarify existing theory (Hutchinson, 1988). With this constant comparative method the researcher is able to change focus, to 'double-back' and to pursue new leads when they are revealed by the ongoing data analysis (Hutchinson, 1988). In Glaser's (1998) opinion:

The bounty of adhering to the whole grounded theory method from data collection, coding and analyzing through memoing, theoretical [sic] sampling and sorting to writing, using the constant comparative method, shows how well grounded theory fits, works and is relevant. Grounded theory produces a core category that continually resolves a main concern, and through sorting the core category organizes the

integration of the theory. Grounded theory is not designed to honor and verify a pet concept of a well know theoretical capitalist. (p. 12-13)

As a systematic package, grounded theory research is able to demonstrate to the reader precisely how the published theory was generated. It is also a method in which the researcher's interactive analytical abilities are of importance for the generation of a substantive theory that illustrates the real world and furnishes new understanding of the social situation from which the theory was generated (Hutchinson, 1988). As Charmaz (2000) observes, for a grounded theory to work:

...it must provide a useful conceptual rendering and ordering of the data that explains the studied phenomena. The relevance of a grounded theory derives from its offering analytic explanations of actual problems and basic processes in the research setting. A grounded theory is durable because it accounts for variation; it is flexible because researchers can modify their emerging or established analyses as conditions change or further data are gathered. (p. 511)

The primary aim of grounded theory approach to research is for a central 'core' category or process to evolve that has a high level of abstraction (Glaser, 2001; A. L. Strauss & Corbin, 1998). In my research this 'core' category has to capture the complexity of actions and interactions undertaken by the adolescents. These (inter)actions employed by the adolescents are in response to their social and cultural experience with their diagnosis and the use of stimulant medication. The adolescents' (inter)actions are designed to accommodate the social processes that emerged from their social interaction while they seek to manage their lives. The 'core' category, "in an exaggerated sense, ... consists of all the products of analysis condensed into a few words that seem to explain what [this research was all about]" (Strauss & Corbin, 1998, p. 146). The power of the 'core' category is its ability to form a "network of interrelated, conceptually dense, categories that collectively represents the phenomenon under study" (Chalmers, 1998, p. 92).

The fundamental grounded theory method strategies used in my research will be explained in detail later in this chapter under data coding and analysis procedures. Briefly these strategies are: simultaneous collection and analysis of data; a three stage

coding process of open, axial and selective; constant comparative methods; theoretical sensitivity and sampling to fine tune the emergent theoretical notions and memo writing directed at the construction of conceptual analysis and the integration of the theoretical framework.

Rationale for using the Grounded Theory Approach

Current AD/HD research is for the most part dominated by quantitative research that derives its data and formulates theories related to the experience of adolescents from the received wisdom of members of the medical profession, teachers and parents (see chapter two). The grounded theory method through which phenomena are studied in the context of empirical data seeks to overcome this issue.

Utilising grounded theory method allowed me to view the world of adolescents with AD/HD from within the realm of their individual consciousness and subjectivity, based on their beliefs, understandings and experience of what was going on, as opposed to the perceptions of the observers of the action, that is their parents, teachers and the medical profession. Nevertheless, human existence, as Hutchinson (1988) argued, is based on social interaction that is governed by symbolic constructions that emerge from and are related to, the reality that is the experience of social life. Depicting the voice of others was, however, fraught with difficulties particularly in a field such as mine where the experience of those with AD/HD has been defined and categorised by others - parents, teachers and doctors. The choice of grounded theory method, as a method that focuses on the perceptions of others, was significant for my research because as Glaser (2001, p. 158) affirmed, "the struggle over how the voice is heard and related in research writings is non-existent in grounded theory. It is all data to be conceptualized for theory, however, the data comes". In grounded theory patterns and concepts are labelled as categories, these categories draw a picture of what is going on; what is indicated by each incident and what is happening in the data as abstracted patterns of behaviour. Grounded theory looks not at the participant's voice per se but at the patterns of behaviour that the voices of many indicate and that these patterns fit, work and are relevant to the behaviour the voices try to represent (Glaser, 2001).

One task of the researcher in a grounded theory study is to depict and unravel the interdependency between the individual and society, for in Chalmers' (1998)

opinion, you cannot understand one without understanding the other. The intention of the data collection and analysis in my research was, therefore, to construct a picture of how the adolescent participants with AD/HD perceived they manage their lives at home, in school and in their social environment. The story that emerged was based on identifying how each individual adolescent with AD/HD constructed their perspectives and then comparing and contrasting these individual constructions one with another. Grounded theory with its rigorous approach to data collection and analysis furnished my research with a clear set of guidelines from which to build explanatory memos and diagrams that specified relationships among concepts. A theory was not, therefore, imposed on the data but rather the results of the analyses were arrived at inductively according to grounded theory convention.

Chapter three acknowledged that a study underpinned by the interactive paradigm and symbolic interactionism was subjective and determined by the researcher's own worldviews, their interaction with others and their interpretation of how others construct their reality. Chapter three also drew attention to the point that research such as mine cannot be value free. I, therefore, endeavoured at all times to ensure that as Lincoln and Guba (1985) suggested the "values inherent in the research process are explicated and explored as part of both the initial and final research processes and products" (p. 182). Focus was also directed in my research towards the relationship of wider issues associated with the phenomenon being studied to acknowledge and account for those relevant wider issues that had a bearing on, or relationship to, the analysis. This was accomplished during the analysis process through the study of relevant documents and comparing and contrasting them with the interview data. Glaser (1965) argued, however, that while a knowledge and integration of the literature relevant to the area being studied was important, it was not necessary for theoretical completeness for all associated literature to be included. In Glaser's (1965, p. 126) view the researcher's "job is to contribute to this literature, not completely to master it". My research acknowledges and accepts the positions outlined above with its use of grounded theory methodology that has the ability, through microanalysis, to link macroscopic issues with the phenomenon being investigated.

The need for a researcher to appreciate cultural differences in research with groups other than their own was discussed in chapter two. Morse (2001) also highlighted this need in grounded theory studies. As Morse pointed out while

grounded theory is a process of labelling categories that explain identified processes, if a process is not labelled the study becomes limited by this imposed selection that "forces the theory into an ethnocentric mold [sic]" (p. 722). Noting where cultural influences were involved, or where they had a bearing on certain issues were, therefore, to be taken into account throughout my research. Morse went on to emphasise that:

The real power of the [grounded theory] method lies with the researcher, not the method, not the strategies. It is the researcher's ability to sensitively perceive and conceptualize, balancing the grounding in the literature, the data, and the cultural context, that ultimately produces an excellent study. (p. 722)

The issues examined in my research focussed on the unique experience of adolescents in WA who were diagnosed AD/HD and receiving stimulant medication treatment and how they managed their lives, rather than viewing the adolescents lives through the eyes of their parents, teachers and doctors. The phenomenon was examined through the grounded theory method; a substantive theory was generated about the phenomenon that explained the social problem encountered by these adolescents and the complex basic social-psychological process by which they tried to resolve the difficulties that they encountered.

Data Collection Process

Introduction

The previous discussion on procedures indicated data gathering and analysis in the grounded theory tradition is an ongoing process. In this chapter, however, I have differentiating data gathering from data analysis simply as an artificial separation designed to assist the reader.

Data were obtained from several sources: face-to-face conversational interviews, focus group sessions, telephone conversations, semi-structured interviews, participant observation and relevant documents and literature. The interview questions used in the various interviews and focus group sessions with the participants were based on a set of formalised interview questions. These formalised questions will be

presented prior to the discussion on data collection. The majority of data were sourced from over 30 audiotape recorded individual interviews with seven adolescents in WA diagnosed with AD/HD as well as from two focus group sessions. These data were collected over a period of seventeen months from July 2001- December 2002.

As the primary focus of my research was directed at establishing the experience of a group of adolescents in WA with AD/HD and how they managed their lives, my research did not include the opinions of teachers, parents or the medical profession. Balance was sought in my data analysis through theoretical sampling with both the initial participants and a further group of three adolescents with AD/HD in the third phase of my study (see profile of the research population). Seeking further participants for theoretical sampling was consistent with grounded theory tradition. Theoretical sampling is explained in more detail later in chapter four. Documents written by adolescents with AD/HD outside of WA were examined and applied to the data to further enhance it. Guidance was also sought from literature relating to recent studies with adolescents with AD/HD. Adopting this stance was in line with the discovery model of theory development in which the initial literature review sought only to establish the purpose of the study, its background and significance. Subsequently, literature was used to identify and draw out data relevant to each stage of the study. Literature, in grounded theory studies, is therefore, an initial source of information and, thereafter, forms a data source (Glaser, 1998; Iruita, 1990; Strauss & Corbin, 1998).

Qualitative research by its nature tends to occur over an extended period of time and involves investigation of a unit through repeated observation in order to observe changes as they develop over time (Bijleveld et al., 1998). It is through these repeated observations that change can be understood or causality explained. The notion directing my research was that by uncovering the changing opinions, experiences, needs and problems of adolescents with AD/HD over a period of time the data obtained would be broader and more informative and thus more illuminating. Bijleveld et al's (1998) admonished researchers to remember that, as behavioural science long term research has indicated, changes do not occur as a gradual process but suddenly and in distinct stages. Nevertheless, it was also of critical significance in my research to adopt the stance of Schulsinger, Mednick, and Knop (1981), particularly as it related to theory building. Their position was that each observed unit

of time should be viewed in cross-section relative to each other and not as a series of unique distinct units observed on several different occasions. With these thoughts in mind I focussed on a discrete time data collection method for identifying transitions in opinions and experiences.

It is now my intention to discuss how each aspect of the data collection process was carried out and the strategies that assisted this process. First, I commence with a discussion on the interview questions that were used in the face-to-face conversational interviews and focus group sessions and how these questions were introduced to the participants in my research.

Interview Questions

The initial questions (Appendix D) were formulated in order to elicit information from the adolescents in response to the central research question. The questions, outlined below, were designed to reflect the central aspects of the symbolic interactionist approach which are: that human beings act towards things on the basis of the meanings they assign to them as symbolic attributions and that these symbolic meanings are derived from social interaction. These interview questions were modified for the semi-structured interviews in phase three as befits the theoretical sampling phase of data analysis which seeks to illuminate and extend emergent constructs. Embodied in grounded theory methods are procedures for inductively developing theory about the central research question from data generated through investigative guiding questions. An overview of these questions follows:

1. In what ways do adolescents in WA with AD/HD perceive their diagnosis and stimulant medication usage?
2. To what extent does a diagnosis of AD/HD and the subsequent use of stimulant medication impact on the adolescent, at home, in school or socially?
3. In what ways do adolescents in WA with AD/HD consider their diagnosis and the use of stimulant medication engenders the needs and problems they experience, at home in school or socially?

4. What, in the opinion of the adolescents, are the most significant needs and problems; to what extent does identifying these needs and problems help them to manage their lives at home, school and socially?
5. What coping strategies do adolescents in WA with AD/HD use to overcome their difficulties?
6. How and to what extent do these strategies change over time?
7. To what extent do these coping strategies assist them in managing their lives?

These questions were not propositions to be proved but rather they formed the basis for uncovering information. It is characteristic of the grounded theory that it should seek out meaning, constructs, problems and process from the perspective of the those involved in the action in this case adolescents with AD/HD, rather than the observers of the action.

An *Aide Memoire* was used to develop the less formal style of interview questions that were actually used in the data collection process. The *Aide Memoire*, as a research technique, was identified by Minichiello, Aroni, Timewell and Alexander (1995) and Chalmers (1998). This technique is used to breakdown investigative questions so that participants more easily understand them. For example:

1. Tell me about being diagnosed AD/HD.
2. Why did you feel the need to go to the doctor?
3. What does being AD/HD mean to you?
4. What treatment did the doctor suggest for you?
5. How do you find using stimulant medication?

6. Tell me about your experience.

Figure 1 demonstrates how an *Aide Memoire* was constructed for my research.

First, Guiding Question:	Examples of questions in an initial <i>Aide Memoire</i>
In what way do adolescents in Western Australia with AD/HD perceive their diagnosis and stimulant medication usage,	<u>Aims and intentions</u>
	1. Why did you feel the need to go to the doctor? 2. What treatment did the doctor suggest for you? 3. Tell me about being diagnosed AD/HD.
	<u>Reasons</u>
	For each of the questions above, probe the adolescent. Lots of "why" questions related to their aims and intentions.
	<u>Significance</u>
	For each of the questions also probe with regard to the significance they attach to their aims and intentions such as:
	What does being AD/HD mean to you?
	How do you find using stimulant medication?
	Tell me about your experience.

Figure 1. The Development of *Aide Memoire* questions from the first guiding questions⁷.

The way in which the questions were worded at the interviews was based on the age and perceived cognitive ability of each adolescent. The order in which questions were put to the adolescents in the face-to-face conversational interviews and focus group sessions did not necessarily follow any set pattern; the participants were permitted to speak freely on any aspect they wished, the questions specifically relating to my research being interspersed throughout the conversations when appropriate. As my research progressed and a greater depth of understanding was sought relating to the experiences of the participants, further questions evolved. These questions were designed to clarify points from face-to-face interviews and focus group sessions, such

⁷ Source: Adapted from Chalmers, Unpublished PhD thesis, University of Western Australia, 1994

as: identifying the problem that most concerned the adolescents, elaborating on the social process developed by each of the adolescents with AD/HD to mitigate this problem and how they managed their lives. This style of questioning was also employed in the semi-structured interviews in phase three.

Data Collection Period

All data were collected between March 2000 and December 2002. The interviews were conducted from July 2001-November 2002, with the majority being conducted during the period August 2001 to June 2002. As Strauss and Corbin (1990, p. 59) asserted, however, "data collection and data analysis are tightly inter-woven processes and must occur alternately because the analysis directs the sampling of data". Distinguishing the data collection period from the data analysis at this point in the thesis is, therefore, for the information of the reader only.

Throughout the period of my research I consulted separately with experts and fellow experienced researchers in the field of grounded theory on aspects relating to the study, its analysis, coding and memo writing strategies and results⁸.

In order to maintain an open mind and focus on the unique experience of adolescents diagnosed with AD/HD, documents and literature sources specifically targeting the viewpoints of adolescents formed an additional source of data.

Sampling Strategy

A purposive sampling strategy was used to identify the participants. Two private paediatricians, three Child Development Centres and one Child and Adolescent Mental Health Service Department in the Perth Metropolitan Area of WA were contacted with a view to locating willing participants. In order to make these requests I first visited the specialists and followed this visit with a formal letter of request (Appendix A). Participants had to meet the following criteria: adolescents (both male

⁸ Monthly seminars coordinated by Professor Irurita were most helpful. Professor Irurita was one of the First, in Australia in consultation with both Glaser and Strauss to use the grounded theory method for her highly acclaimed PhD dissertation. Professor Irurita regularly supervises and examines PhD's and Masters theses. She has published widely in the field, is an invited keynote speaker at international conferences, and has undertaken two further grounded theory studies. Professor Irurita lectures in grounded theory at Curtin University of Technology, Western Australia. Her input and that of fellow researchers served to reduce bias and bring a broader more informed perspective to my research.

and female) in WA from 12 to 20 years of age with AD/HD clinically diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders - DSM IV (American Psychiatric Association, 1994) - with no diagnosed comorbidities. The diagnosis had to have been made by a paediatrician or psychiatrist according to two subtypes - Attention-Deficit/Hyperactivity Disorder Combined Type (AD/HD-CT) and Attention-Deficit/Hyperactivity Disorder Predominantly inattentive Type (AD/HD-PI). A total of 52 adolescents with AD/HD were identified as meeting these criteria. These 52 adolescents and their parents were then invited by the paediatricians or health departments to participate in my research project. Twelve families expressed an interest in my research and agreed to their names, addresses and telephone numbers being passed to me. I then made contact with these 12 families by means of a formal letter of invitation to participate accompanied by a consent form to be signed by both the adolescent and their parent or guardian confirming their agreement to participate in my research (Appendix B and C) (as discussed in chapter three). I followed up with a telephone call to introduce myself and clarify any issues that the families or adolescents raised and discuss my research. Of the 12 families contacted, seven agreed to participate in my research. Five of these adolescents with AD/HD were male and two were female. One male adolescent was unable to proceed with the project. Subsequently, a further female adolescent with AD/HD agreed to participate. She was unable to join the project until sometime after the first group of six participants. This final group of seven adolescents with AD/HD (four male and three female) were the principal participants in my research. A further group of three older adolescents with AD/HD, aged 18-20 years were invited to participate as directed by data analysis findings. The inclusion of these participants will be discussed shortly under the section entitled theoretical sampling.

The decision to include both males and females diagnosed with the two subtypes AD/HD-CT and AD/HD-PI was based on research that indicated that boys were more likely to be diagnosed AD/HD-CT than girls who were more often diagnosed AD/HD-PI (Faraone et al., 2000). According to Biederman et al. (1999), it was questionable whether this difference was substantiated or a result of AD/HD research being almost exclusively based on male subjects and, therefore, girls with AD/HD-CT were under identified. From the perspective of my research, however,

targeting both types of diagnoses ensured that a cross section of the adolescent population in WA with AD/HD (albeit small) was included.

Profile of the Research Population

Of the seven principal participants three adolescent males were diagnosed AD/HD-CT and one adolescent male was diagnosed AD/HD-PI, two female adolescents were diagnosed AD/HD-CT and one adolescent female was diagnosed AD/HD-PI. At the commencement of data collection in July 2001 these participants' ages ranged from 12-17 years. A further three participants, one female and two male, aged 18-20 years joined my research at the theoretical sampling stage (see subsequent discussion). The demographics of the research population were wide ranging, covering a broad socio-economic base. All of the initial participants attended secondary schools in the Perth metropolitan area. Of the three adolescents who joined at the theoretical sampling stage two lived and studied in the Perth metropolitan area. The remaining participant usually lived in the Eastern States but was staying in WA at the time of the data collection phase. Given the dearth of WA participants and as the theoretical sampling stage of grounded theory research is specifically aimed at clarifying points in the data and his views were deemed relevant to my research I decided to include him in my research, even though he was not a permanent resident in this state.

The choice of the adolescent stage of development as the period in which to locate the choice of research participants came about for two reasons. First, current research indicates that the experience of adolescents with AD/HD is rarely documented and because they tend to have low self-esteem, under achieve scholastically and be inclined to higher risk taking behaviour their parents tend to be the decision makers. Second, the adolescent is regarded by society as someone to be guided and shaped by external forces to ensure they conform to social expectations. Society regards adolescents as subordinate social problems that need to be resolved (Corsaro, 1997); in other words they are marginalised. Nevertheless, as A.B. Smith, Taylor, et al. (2000) argue, if adults are to ameliorate the problems that affect children, young people and their families, they need to develop a clearer understanding of how the lives of children and adolescents are constructed. The childhood expert is the child or young person themselves. It is they who best understand their own lives and experiences. It, therefore, behoves adults to listen to the voice of the child or

adolescent, as fundamental partners in the creation of better life outcomes, not as independent actors, but as competent members of families who are also entitled to their own point of view.

Theoretical Sampling

According to Strauss and Corbin (1998), the grounded theory method depends on two operations for the development of theory. The first, is asking effective questions that are aimed at augmenting understanding of the theoretical issues. These questions sensitise the researcher to what is going on. At the same time theoretical questions are asked of the data in order to develop connections among concepts and guide the researcher in the analysis of interviews, observations and relevant documents. In the second operation incidents are compared one with another to classify them and theoretical comparisons are used to stimulate thinking about properties and dimensions so as to direct theoretical sampling. It was this second operation that primarily directed the third phase of data collection in my research during which further data were sought not only from the seven initial participants but also three additional participants. Theoretical sampling in this third phase was directed by the need to further explore the categories their properties and dimensions. With theoretical sampling the researcher is seeking relevant data to augment the evolving categories and theoretical codes, to identify variation and to discover data that may lead to a greater understanding of the developing theme, or data which indicates new properties of the categories or processes (Glaser, 1978; 1998; 2001; Hutchinson, 1988; Strauss & Corbin, 1998).

While theoretical sampling is a continuous process throughout a study, it becomes a more discriminating process in the later stages of data analysis. To accomplish this in the later stages of data analysis the researcher "chooses sites, persons and documents that will maximize opportunities for comparative analysis" (A. L. Strauss & Corbin, 1998, p. 211). According to Glaser, the theoretical sampling process is controlled by the emerging theory. It, therefore, behoves the researcher to constantly interact with the data to identify further areas for sampling. In Glaser's words (1998, p. 157) "theoretical sampling is the conscious, grounded deductive aspect of the inductive coding, collecting and analysing. It is grounded deductions, feeding into data for more induction as the growing theory leads the researcher on."

With these thoughts in mind I repeatedly returned to the field to converse further with all participants either face-to-face or by telephone; to expand upon, explore, or check data already received and to develop the theoretical relevance of concepts. Additional participants were sought as directed by the data when a more deliberative style of theoretical sampling was indicated. In this way the three older adolescents with AD/HD were approached to participate in the research. These adolescents had left secondary school and were either receiving tertiary education (apprenticeship, university) or were involved in business. The selection of older adolescents with AD/HD at this point in my research was based on the view that the theoretical sampling should now be more deliberate and discriminatory as it was aimed at theory verification. It was envisaged that the reflective approach of older adolescents as to how they managed their lives would enhance the data analysis in my research. This approach, referred to as targeting (Irurita, 1990), seeks to aid verification, clarification, elaboration and corroboration of information obtained from initial participant interviews. This targeted approach was also employed to verify information about issues that appeared to be controversial or sensitive in the data.

For this theoretical sampling phase (identified later as Phase Three) semi-structured face-to-face open-ended interviews were employed. This style of interview was preferred for this deliberate theoretical sampling as it facilitated the pursuit of specific issues that emerged as being significant to my research (Patton, 1990). Returning to the field to corroborate, or expand upon data was identified as an important strategy by Glaser (1978; 1998), Gregg and Magilvy (2001) and Strauss and Corbin (A. L. Strauss & Corbin, 1998). Phase three interviews continued until saturation of the theoretical core category had occurred, that is, no additional data were discovered to develop new categories or properties of the categories.

Documents and Literature

Documents and literature sources were used, where appropriate, throughout the data collection and analysis. The literature review established the background and the significance of the phenomenon I intended to research. Once data coding had commenced themes and conceptual categories were identified then further literature reviews were undertaken as part of the continuous comparative process of data collection and analysis. These literature reviews were specifically designed to develop

and illuminate the conceptual categories as they emerged from the data. Care was taken to avoid researcher bias and to allow concepts to evolve from the participants' unique thoughts, ideas and experiences. This was accomplished in several ways first, by rigorous checking of data with the participants to ensure that I comprehended their meaning relating to issues and problems and was not superimposing my cultural perspective on their unique thoughts. Second, additional documents germane to information collected during the interviews were sought to expand upon information elicited through the interviews. As categories became more refined, specific data were sought from texts by adolescents diagnosed with AD/HD in other areas of the world, to validate and expand further upon information derived from the interviews. Third, data comparisons were made with two recent qualitative studies undertaken with adolescents diagnosed with AD/HD, one in South Australia and one in the United Kingdom (Cooper & Shea, 1998; Prosser, 2000).

A final comprehensive study of current AD/HD research was undertaken when the data collection was completed. The theory that evolved from my research was compared to existing research and theories inasmuch as the substantive theory developed in my research is presented in the context of the existing theories.

Phases and Phase Interviews

Introduction

Face-to-face, open-ended conversational interviews and focus groups were chosen as the primary means of information collection for my research. This in-depth form of interviewing takes the form of a conversation between the interviewee and the interviewer. This style of interviewing "focuses in an unstructured way on the informant's perception of themselves, of their environment and of their experiences" (Burns, 1994, p. 208). Rather than waiting for all the participants to consent to participate in my research the interviews in phase one commenced, as each participant was located and consent to participate was given by them and where appropriate their parents. As previously noted the parents did not participate in my research, however, their consent was required when an adolescent was under 18 years of age. The first appointment was made for a time and at a venue convenient to the adolescent and their parents.

The interview questions were designed to guide data collection and analysis in ways that highlighted the voice of the adolescent with AD/HD and accounted for their unique perceptions and experiences with regard to their disorder and their utilisation of stimulant medication as a treatment modality. The impact of their diagnosis and treatment on their home, school and social life was studied and how or whether their perceptions changed over time. The focus of my research was the way in which the adolescents diagnosed with AD/HD managed their lives; the issues and problems encountered by these adolescents and the process by which they managed their lives and try to resolve the difficulties that they face.

Phase One.

In phase one of my research a total of seven adolescents with AD/HD (four males and three females) participated in a series of 25 face-to-face open-ended conversational interviews over a period of approximately nine months. The original intention was for all of phase one to be completed before the commencement of phase two. This was not possible as one participant (a female) only agreed to take part in my research sometime after the other participants had completed this phase. Remembering the adage that 'all is data' and as the numbers involved in my research were relatively small I did not wish to dissuade her from participating. Particularly, as will be discussed shortly, when other participants in my research had expressed reservations about the format of phase two.

The second and third and sometimes fourth interviews with each participant took place in similar circumstances to the first. There was an interval of approximately one week between the first and second interviews and one month between the second and third and third and fourth interviews. The majority of interviews took place in the participant's home with the parents present at the house but not in the same room. One older participant preferred a busy coffee shop; in this instance the parent was not present. The participants were telephoned between interviews to clarify data furnished by them.

Face-to-face open-ended conversational interviews.

The aim of in-depth interviewing is as a free flowing conversation dependant upon social interaction between the two interlocutors. The interview is kept as natural as possible, however, where necessary the interviewer directs the conversation to

ensure that the focus of the interview is maintained (Burns, 1994). The purpose of in-depth interviewing in my research was to develop an understanding of the experience of adolescents with AD/HD and the meaning they made of that experience. As Seidman (1998) observed, in-depth interviewing is not about getting answers to questions, testing hypotheses or evaluating but rather it is about comprehending and understanding the actions of others. It is about having "an interest in other individuals' stories because they are worth it" (Seidman, 1998, p. 3).

During these interviews the participants were permitted to talk without time limits being imposed on them. They were asked to discuss their experience of the diagnosis of AD/HD and the use of stimulant medication in relation to their impact on their home, school and social environments and how they managed their lives. This discussion included what they thought being AD/HD meant to them; their experience of medication; what facilitated and(or) inhibited them in the management of their lives, the problems encountered and their relationship to their diagnosis and use of stimulant medication and how they dealt with these problems.

I usually commenced the interviews by explaining that the aim of the research was to understand their unique experience of their diagnosis of AD/HD and the use of stimulant medication, not the views of their parents, their teachers or their doctors. The participants were repeatedly assured of confidentiality at all times; this last point was particularly important as many parents expressed a desire to discuss their adolescent's behaviour with me, while some sought to ascertain what their adolescent had said during the interviews. A general discussion followed the preliminary procedures until the participant appeared relaxed. More specific questions were then introduced for example: "What problems did you experience before you went to visit the doctor?"; "What does being AD/HD mean to you?"; "What is your experience of the medication?"; "What are your thoughts on the medication?"; "In what way has this affected you at home, school and with friends?" (this last would have been introduced as three separate questions). Other probes were introduced at appropriate times during the conversation to explore these topics such as: "Give me an example of what this means to you"; "In what way did this affect you?"; "What in your opinion was the greatest problem you experienced?"; "How did you cope with this and other problems?"; "What in your view are your greatest needs?" As previously indicated the

Aide Memoire strategy (Minichiello et al., 1995) furnished my research with avenues to explore each of the formal investigative guiding questions (Appendix D).

As I began to know the participants they became more open and spoke freely, taking the opportunity to discuss issues of particular importance to them such as the comparison between social drug taking and stimulant medication use. In addition, as my research progressed many participants expressed the view that talking with me had allowed them the opportunity to gain a greater understanding of themselves, their diagnosis and stimulant medication use and the impact they believed these issues had on their lives. For some it enabled them to appreciate their strengths and coping capabilities. Several expressed the view that the discussion had been of benefit to them "Now I can talk about it instead of keeping it to myself and can talk, tell someone and talk to someone about it" (RB Focus group debrief, 214-215)⁹.

In some of the interviews I was regarded as an informed source of AD/HD information and as such was required to adopt an educative role. For example, information was sought on current AD/HD research, particularly that relating to medication safety; as well as literature related specifically to adolescents and young adults. Engaging in this way with the participants did not intrude on the data, as it usually took place at the end of an interview or during telephone conversations. I regarded this interaction as important, not only in light of my current research but also my work in schools and the findings of previous studies undertaken (Carragher, 1997; 1999). The findings of these unpublished studies and the knowledge I gained through my work in schools are in line with other AD/HD research such as that presented in the International Consensus Statement (Barkley, Cook, et al., 2002), discussed in chapter two.

The interviews in phase one with each of the seven principal participants took on average 30 minutes, the shortest lasting 20 minutes and the longest 3 hours. The audio tape recorder malfunctioned on one occasion in phase one. When this was discovered at the culmination of the interview I made detailed notes of the conversation, recalling as much as possible.

⁹ The numbers in this quotation refer to the line numbers of the extract. A copy of each interview is located in QSR NU*DIST (to be discussed later).

The recorded interviews were transcribed as Microsoft WORD documents with the participant's code name, interview number and the date being recorded. Each of the interviews were transcribed by me in their entirety and verbatim, notations were made to indicate pauses and exclamations by the participants. As the data collection progressed it became obvious that a more effective platform than Microsoft WORD was required to cope with the large number of code words, concepts and categories. QSR NUD*IST 4 software was chosen to fill this role. The transcribed interviews were reformatted so as to facilitate their input in the NUD*IST software (to be discussed in chapter four).

Phase Two

Phase two of my research consisted of two focus groups. The first consisted of three adolescent males with AD/HD; of these three, two were diagnosed with AD/HD-CT and one with AD/HD-PI. The second focus group was a mixed group consisting of one adolescent female diagnosed with AD/HD-PI and one adolescent male with AD/HD-CT. It was my original intention to have two gender distinct groups to avoid the 'peacock syndrome', a phenomenon induced when a group is not gender specific (Kreuger, 1994; Vaughn, Schumm, & Sinagub, 1996). This did not prove possible for the following reasons: First, one of the seven principal participants involved in my research (as noted previously) commenced some three months later than the other six, so was not available to be included in phase two. Second, although all six adolescents in the initial group were eligible to participate, one of the two female participants declined to participate in a focus group, citing fear of talking in public as her reason. Third, one of the four male participants elected to participate in a small group of two participants of like age citing similar reasons to those of the female participant already mentioned. Due to the small numbers in my research the only remaining participant was female and, therefore, focus group two was a mixed male female group that brought with it, as anticipated, its own unique problems in line with those outlined by Kreuger (1994) and Vaughn et al. (1996). Focus group one was conducted at Edith Cowan University, Mount Lawley. The participants in focus group two chose a park near the home of one of the two participants.

Focus group interviews.

Focus group or group interviewing, according to Morgan (1997), was first alluded to in the social sciences by Bogardus in 1926. They were regarded as notable tools in the examination of the effects of propaganda and the effectiveness of training materials for the troops during World War II. Lazerfeld, while at Columbia University, made use of focus group interviewing in the 1960s and early 1970s. Over the ensuing decades focus group interviewing fell from vogue and did not feature strongly in social science research until the late 1980s and 1990s when it returned to prominence (Morgan, 1997).

In focus group interviewing a relatively homogenous group of people are asked by the interviewer (who takes the role of moderator) to reflect on a series of topics. As an interactive process, focus groups allow participants the opportunity to listen to the responses of others in the group, to add their own comments, or formulate their own responses to the topics under review (Morgan, 1997). The objective of a focus group is "high-quality data in a social context where people can consider their own views in the context of the views of others" (Patton, 1990, p. 335). The group interview "gives rise synergistically to insights and solutions that would not come about without them" (Patton, 1990, p. 17).

Focus groups in the main require a greater level of researcher control (Morgan, 1997; Vaughn et al., 1996), however, the less structured format employed in my research gave each group control over the direction of their discussion. The participants were able to direct the focus group because I, as researcher, handed the interview over to the participants and only interjected questions where necessary. As the unstructured interviews in phase one permitted the participants to discuss their individual experiences in such depth as they themselves chose, so too the focus groups in phase two allowed the participants to choose the direction for discussion. In my research, focus groups were used to supplement data from the individual interviews as a platform that facilitated the emergence of further data. The focus groups thus enhanced the data garnered from the participants in earlier interviews. The focus groups also provided their own unique contribution to the phenomenon under study in my research.

In both focus groups the preliminary discussion was of a general nature. By now the participants were at ease with me and commenced discussion about AD/HD

and its impact on them of their own volition. Questions were interjected where necessary by me to maintain the focus on topics associated with the impact of AD/HD and stimulant medication use on the adolescents and how they managed their lives. The questions used in these group session followed similar lines to those in the face-to-face interviews and were developed, as before, from the formal guiding questions through the *Aide Memoire* strategy (Minichiello et al., 1995).

The audiotape recordings from the interviews were transcribed as in phase one. Substantive and methodological field notes were made to record the observations made from the video recording of focus group one and notes were taken during and after focus group two. These notes, as before, were transcribed into a Microsoft WORD document and then later transferred into QSR NUD*IST 4.

Focus group one.

Focus group one consisting of three adolescent males with AD/HD lasted a total of 2 hours 30 minutes, there were, however, several breaks during the discussion to allow participants to walk around and stretch their legs. This was particularly necessary given that these adolescents had AD/HD and maintaining focus was difficult for them. The focus group was audiotape recorded with permission from the participants. This group interview was also videotape recorded in order for me to observe the participants' actions and mannerisms. Again the participants gave their consent to this.

Focus group two.

Focus group two took place in a park adjacent to the home of one of the participants. The group consisted of one male and one female adolescent with AD/HD (as previously discussed). This interview lasted for 1 hour 30 minutes during which time the parents of one of the adolescent's drove past on several occasions to check all was in order. The recording of this focus group interview was somewhat constrained by its venue. As before it was audiotape recorded, however, it was not possible to use a video camera to record the actions and mannerisms of the participants. I, therefore, made careful notes during and immediately following the interview to record these details.

Phase Three

Phase three of my research involved a final semi-structured face-to-face interview with each of the seven participants. In addition, a further group of three older adolescents with AD/HD had consented to participate in this phase of my research. A total of ten interviews were completed in this phase. These last ten interviews formed the basis for the final deliberate and discriminatory phase of theoretical sampling. The intention of these last interviews was to clarify points made in previous interviews, expand data sources and "to integrate the categories along the dimensional level to form a theory, validate the statements of relationship among concepts and fill in any categories in need of further refinement" (A. L. Strauss & Corbin, 1998, p. 211). These interviews in phase three were, therefore, highly selective. The interviews were conducted in similar circumstances to those of phase one of my research. Phase three was undertaken after phases one and two were completed.

Semi-structured face-to-face interviews.

As the aim of phase three was deliberate discriminating theoretical sampling, in consequence a more structured standardised format was appropriate (Burns, 1994; Patton, 1990). In order to bring a more standardised approach to the interviews the semi-structured interview format incorporated an interview guide as a systematic process in which similar questions were asked of each participant. These questions were still based on the formal guiding questions (Appendix D), but where data required further clarification other appropriate questions were introduced. This style of semi-structured interview proved germane as the need was for an evaluative tool to expand upon and clarify data. The semi-structured format facilitated my directing interviews to focus on issues crucial to my research. The aim of this interview format was to reduce variation among interviews as the technique sanctions the researcher to carefully collect the same information from each participant. The open-ended style of these interviews with a conversational approach was maintained. In consequence, as Burns (1994) and Patton (1990) argued, it allowed for the data collected remaining the thoughts and insights of the participants. According to Burns, this style of interview allowed greater flexibility than the close-ended type of interview, while still permitting a more valid response related to the participant's perception of reality. The semi-structured style of interview approach may be somewhat limiting, however,

when topics or issues not anticipated during question construction are not pursued. Nonetheless, its more formally constructed design was arguably effective in the later stage of this grounded theory study when specific theoretical information and clarification were sought from participants as the process of theoretical sampling. This act of returning to the field to verify data has been, according to Cutliffe and McKenna (in press), supported by an abundance of literature. Moreover, as Glaser (1978; 1998) and Strauss and Corbin (1990; 1998) asserted, it was essential to return to the field not only for theoretical sampling, but also if saturation of the core category was to occur.

Each interview in phase three with the seven original participants lasted on average 25 minutes, with the shortest being 20 minutes and the longest one hour. The three interviews undertaken with the supplementary participants lasted approximately one hour each. The interviews were audiotape recorded with consent and transcribed into Microsoft WORD documents (and later into QSR NUD*IST 4). Likewise, notes and memos were again made describing the actions, mannerisms and, nuances observed at the time. The general format for each interview followed those established in phase one.

The interview phases are depicted in Table 2:

Table 2

Timetable for Phases and Interviews

Phase One - Individual Interviews	Interview 1 immediately following consent to participate	Interview 2 - one or two weeks later.	Interview 3 and 4 - approximately one month after the previous interview.
Phase Two - Focus Groups	Focus group two - all male group with 3 participants - one month after completion of phase one interviews	Focus group two - one female and one male adolescent with AD/HD - one month after completion of all the phase one individual interviews.	
Phase Three - semi structured face-to- face interviews as deliberate discriminating theoretical sampling	Final semi-structured face-to-face deliberate theoretical sampling interview with all seven initial participating adolescents with AD/HD - two months after completion of phase two	Deliberate theoretical sampling semi- structured face-to-face interview with three further participating adolescents with AD/HD - two months after completion of phase two.	

In total, in excess of 45 hours of interviews and focus group sessions were recorded and formed the major data source. Telephone conversation notes and methodological field notes were used in conjunction with these data (see later discussion).

The capacity of qualitative research and in particular the grounded theory approach, for accommodating multiple perspectives facilitated the organisation of my research so that it was able to meet the needs of each situation that was encountered in

the research environment. For example, the accommodation of a new participant within the initial phases of the research.

Throughout my research ethical issues relating to in-depth interviewing and the sensitive nature of the focus of my research were taken into consideration at all times. Although the study was directed by a clearly designed plan, the plan was not rigidly adhered to and changes were made when necessary to accommodate the wishes of participants.

Concurrent Information Gathering

Observation notes were made throughout the data collection period. Telephone contact was also maintained with the participants. These two strategies were employed concurrently with the other forms of data collection and will now be detailed.

Observation Notes

Detailed observation notes were made in the field during interviews; these notes were consistent with principles and practice outlined by Burgess (1982) and Webb (1982). The notes provided a further source of data specifically related to the interviews. These notes were a combination of substantive field notes and methodological field notes. The time, date and place were recorded on each note and these notes were transcribed for ease of retrieval. Printed copies of these notes were placed in a loose-leaf research diary. Listening, watching and thinking are the foundations for note-taking and marked the preliminary analysis phase and theoretical discovery. These substantive field notes focussed mainly on nuances observed and identified recordings and observations from interviews and focus groups.

Methodological field notes formed a record of my personal impressions of situations and included details such as participants' relationships with others. In line with the thinking of Burgess (1982) these methodological field notes also included my own thinking relating to incidents or issues that occurred during the interviews. Constructing methodological field notes in this way serves an important function in moving the methodology and analysis forward. They may be regarded as "conversations with oneself" through which insights and leads are developed and

direct the analysis forward to future action (Ely, with Anzul, Friedman, Garner, & McCormack Steinmetz, 1991, p. 80).

These substantive field notes and methodological field notes formed the basis for memoing, a grounded theory strategy that will be discussed later in chapter four.

Telephone Conversations

Between interviews telephone contact was made with the adolescent participants. This medium proved beneficial as it separated the interviewee from interviewer and vis-versa. In doing so, this process removed any stress associated with face-to-face conversations and allowed the adolescents to talk more naturally without being observed. Dillman (1978) had previously noted that telephone conversations were advantageous as a form of interview specifically because they did away with the need for face-to-face communication and thus minimised the stresses associated with answering certain questions.

During the face-to-face conversational interviews I became aware that some of the adolescents reacted with some discomfort to certain questions in the face-to-face one-on-one situation. I was very conscious of the significance of the adage 'do no harm'. Where topics appeared, therefore, to cause concern or even anguish to a participant the subject was discontinued immediately. Later in the conversation another less emotive or anxiety producing question related to that topic was introduced. On occasion, with the more sensitive participants, I became aware that it would be inappropriate for certain questions or topics to be reintroduced. Where a participant was overtly concerned or distressed with any topic this was noted and constituted an integral part of the data. As researcher my perception was that, at times, the interview questions intruded into areas they did not wish to discuss. In a telephone conversation they were free to ignore or brush aside these questions, whereas, in the face-to-face interviews they seemed to perceive a certain obligation to reply to me.

Telephone contact also proved beneficial given the wide geographical distribution of the participants (the Perth metropolitan area extends for approximately 172 kilometres north to south and 40 kilometres west to east). Telephone calls to participants allowed for interviews to be arranged more smoothly and for changes to be made by the adolescents to any previously organised interview schedule. On occasions the adolescents initiated telephone contact themselves. This contact by them

tended to occur later in my research and occurred when they sought information or wished to discuss a problem. For the most part, however, I initiated telephone contact.

*QSR NUD*IST 4 - A Computer Software Tool*

As the magnitude of the data and the limitations of Microsoft WORD as a data analysis tool became apparent QSR NUD*IST N4 Classic, a computer software package, was chosen as the coding platform. The transcribed and specifically formatted files located in Microsoft WORD were reformatted along with the substantive and methodological field notes and memos to allow for their inclusion into QSR NUD*IST N4. This computer package is designed to "aid users in handling non-numerical and unstructured data in qualitative analysis, by supporting processes of coding data in an index system, searching text or patterns of coding and theorising about the data" (Richards, 1998, p. 6). QSR NUD*IST N4 facilitated the management of the large amounts of data that eventuated from my research. It gave me flexibility in the ongoing analysis so that data could be coded and re-coded, sorted into analytical categories and complex patterns within the data and be depicted in the forms of trees (hierarchical patterns). QSR NUD*IST N4 was an effective tool for managing and exploring documents, creating and developing ideas and identifying themes and refining categories. This programme allowed for data segments to be multiply coded and for all codes attached to data to be retrieved individually across all files. The package also allowed for notes and memos to be sorted and retrieved at will and for variables to be compared across all data.

The use of the QSR NUD*IST N4 programme allowed me to spend more time and energy interpreting and analysing the data from my research. Gahan and Hannibal (1998) articulated the programme's usefulness as follows:

Seeing the story in complicated data and finding out what's going on;

Sorting data into theme areas so that all the "stuff" about a theme is in one place and it can be viewed all together;

Locating key words or phrases, sorting them and storing them in one place so that they can be reviewed;

Linking ideas together;

Comparing groups or sites or stages to see how they are different;

Locating all answers for a question and then looking for key ideas expressed in the responses;

Making categories for thinking about the data and to see more general shapes in the data;

Using categories to code data and then examining each category to see what it is referring to;

Doing the data justice - not summarizing it but really exploring;

Re-coding or resorting data which no longer "fits" where it was previously categorized;

Looking to see if there are linkages between categories or theme areas;

Testing or checking to see if a link or a pattern between categories is really there.

Managing or know where all the data is, so it doesn't become lost or misplaced. (p. 3)

QSR NUD*IST N4's ease of retrieval of and the ability to simultaneously collate coded segments on demand, enhanced the reproducibility and generalisability of the findings. At the same time, because each segment of data was given a file name and number if I considered that a segment of data deviated from the intent of that particular code or category it was easily located and a new code applied.

Although QSR NUD*IST N4 was an invaluable coding tool, manual coding of hard copy was still retained as the preferred coding method. As Seidman (1998) remarked, caution should be used when editing data on screen. In his experience (and that of myself), there is a significant difference between how the individual views text on a hard copy and how that same text is perceived from the screen. On screen there is a tendency to miss issues of importance or to not relate issues to one another.

Where QSR NUD*IST N4 enhanced data analysis and theoretical conceptualisation and construction the following computer software package, *Inspiration* ® 7, refined the writing up of the report.

Inspiration ® 7: A Supplementary Computer Software Tool

Inspiration ®7 (*Inspiration version 7: Getting started*, 2002) was used to graphically develop ideas and concepts located in the QSR NUD*IST N4 programme that had evolved from the data. Where QSR NUD*IST N4 facilitated the searching of interview data to develop code words and categories *Inspiration* ® 7, as a graphic design computer software package, allowed me to transform the QSR NUD*IST N4 material into visual diagrams. Working with visual representations of ideas, concepts and categories enhanced my ability to relate one with another. This process also allowed for gaps to be identified in the data and to refine understanding of the data. The diagrammatic style of *Inspiration* ® 7 also encouraged the identification and clarification of the process and the establishment of hierarchical levels of code words and categories in the data.

According to Howlett (1996), visual images promote efficiency and clarity of presentation. They allow readers to comprehend more quickly and clearly the intentions of the presenter. When a diagram is designed coherently the myriad small details combine to transcend the functional nature of the diagram and bring the story it is depicting to life. The final transfer of concepts, codes and categories into software programme *Inspiration* 7 (*Inspiration version 7: Getting started*, 2002) facilitates category development, inter-weaving of codes and categories and the process of story building. Methodological code notes, memos, documents and literature supplemented interview data including those interviews undertaken in the process of theoretical sampling with the intention of further broadening the evolving theory.

Data Coding and Analysis Procedures

Introduction

As previously outlined the data collection is now followed by a discussion on the data coding and analysis procedures. It should be noted, however, that collection of data, coding, analysis and memo writing were undertaken concurrently throughout my research.

Before detailing the coding and analysis process I will outline the steps in the research process discussed so far and then outline the grounded theory format I employed for coding and analysis. The steps in my research follow those delineated by Chalmers (1998), Glaser (1992), Hutchinson (1988), Irurita (1990) and Strauss and Corbin (1990; 1998). For the benefit of the reader these steps are depicted in a sequential fashion. As previously mentioned, however, grounded theory is a constant comparative process in which the researcher is required to move backward and forward as the emerging codes and categories in the data dictate. The grounded theory method, therefore, is both sequential and cyclical in its interplay between micro and macro conditions and consequences. The research process steps were as follows:

1. Acknowledging and allowing for my personal values and preconceptions through self-interview; avoiding the imposition of these biases on data collection and analysis.
2. The collection of data from multiple sources using a variety of methods: face-to-face open-ended conversational interviews, semi-structured interviews, focus groups, examination of documents and literature searches (including background overview of research into AD/HD and adolescent stage of life).
3. Open coding of the data synchronous with commencing data collection; in other words, the analytical process through which concepts and categories that stand for phenomena were identified and their properties and dimensions were discovered from the data.
4. Memo writing and diagramming, i.e., written records containing my thoughts and ideas about concepts and categories and visual tools depicting the relationships among these concepts that emerged during analysis (coding).

5. Theoretical sampling - further data collection, coding and analysis driven by the categories identified and my interpretations or ideas associated with these categories.
6. Throughout the research process the constant comparative method allowed for categories that have derived from problems, issues, concerns and matters that were important to those being studied to be compared one with another. These categories and their properties define data and give it meaning. According to Strauss and Corbin (1998, p. 117), properties are the "general or specific characteristics or attributes of a category". As they become integrated they elevate the data to more abstract levels.
7. The core category leading to the core process that is the crux of the phenomenon around which all the categories revolve now emerged and was delineated.
8. Thereafter, as suggested by Irurita (1990), further deliberative theoretical sampling was entered into (based on the preceding findings). The outcome of this theoretical sampling was coded and analysed and memos and diagrams produced that focussed on the core process, sometimes referred to as the core variable, of the theory.
9. Saturation was achieved when no new information seemed to emerge during coding relating to the core category or process. According to Strauss and Corbin (1998):

...there is always ... potential for "new" to emerge. Saturation is more a matter of reaching the point in the research where collecting additional data seems counterproductive; the "new" that is uncovered does not add that much more to the explanation at this time. (p. 136)

Interviews continued until saturation of the core theoretical category and process occurred, that is, no additional data were forthcoming, to develop new categories or properties of the categories.

10. Reviewing my interpretation of the data both from my own and the perspective of others to establish generalisability, reproducibility, precision, rigour and verification in line with Glaser (1998) and Strauss and Corbin's (1990) rationale

for grounded theory study and Piantanida and Garman's (1999) criteria for evaluating qualitative research (see chapter three).

11. Sorting the memos into theoretical frameworks and writing the report, incorporating existing theories from the literature.
12. Returning to the field for the findings to be reviewed by the participants and non-participants.

The relationship between data gathering and analysis is diagrammatically depicted in Figure 2.

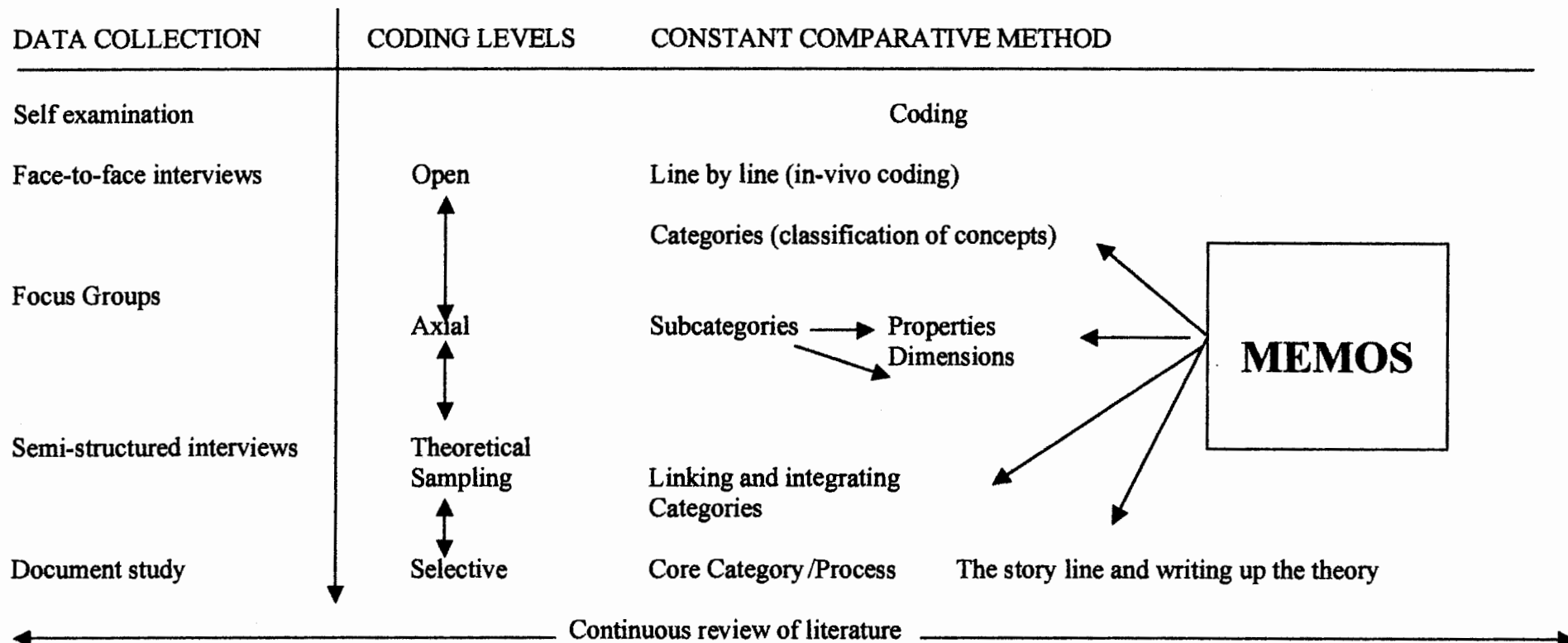


Figure 2. A diagrammatic representation of the constant comparative method of grounded theory analysis. Source: Adapted from Charmaz (1983) Multi-step constant comparative analysis and Chalmers (1998) Constant comparative chart.

In grounded theory the data analysis process involves coding of data. According to Strauss and Corbin (1998), the coding process is one in which data are broken down into concepts, these concepts are compared and contrasted and then integrated to form a theory. The coding process is divided into a series of activities. I now present the coding processes that were applied to the data using the constant comparative method. These are discussed under the following headings: open coding, axial coding, theoretical sampling and selective coding.

Initially, my research focussed on uncovering the notions or concepts of process. This involved analysis of the adolescents' perceptions of their disorder and stimulant medication usage and the corresponding actions that moved the adolescents with AD/HD from one phase to another of self determined management. In order to develop an understanding of process as non-progressive the adjustments made by the adolescents with AD/HD to accommodate the problems they encountered and their changing needs were analysed repeatedly throughout the duration of my research. In the process of interpreting the actions, interactions and behaviours of the adolescents, it was necessary for me to be aware that research such as mine is also determined by my own world views, my interaction with others and my interpretation of how others construct their world as symbolic meaning. Throughout this process being aware that I was an interactive participant within the research, particularly in the context of culture, was a significant factor if the experiences of the adolescents with AD/HD were, as DePoy and Gitlin (1994) argued, to be logically understandable, confirmable and useful.

Coding commenced at the same time as data collection and the concurrent recording of field notes and observations. The levels of coding employed by me will now be discussed in greater detail. To assist the reader and clarify meaning code headings attributable to Straus and Corbin will be applied. Each section also contains a glossary of terms to assist the reader; these are taken from Strauss and Corbin (1990; 1998)

Open coding

A glossary of terms employed with opening coding follows in Table 3.

Table 3

Glossary of terms and meanings employed during the grounded theory analysis¹⁰.

Terms	Meanings
Concepts	Conceptual labels placed on discrete happenings, events, and other instances of phenomena.
Category	The classification of concepts. This classification is discovered when concepts are compared one against another and appear to pertain to a similar phenomenon. Thus the concepts are grouped together under a higher order, more abstract concept called a category.
Sub-category	Concepts that pertain to a category, giving it further clarification and specification.
Coding	The process of analyzing data.
Code Notes	The products of coding. These are one type of memo.
Open Coding	The process of breaking down, examining, comparing, conceptualising, and categorizing data.
Properties	Attributes or characteristics pertaining to a category.
Dimensions	Location of properties along a continuum.

Open coding (A.L. Strauss & Corbin, 1990; 1998) commences with code words that describe the action in the setting, such codes are referred to as substantive or in-vivo codes. According to Glaser (1998), Hutchinson (1988) and Strauss and Corbin (1998), these codes may make use of the exact words employed by the

¹⁰ Source: Strauss and Corbin (1990, p. 61; 1998, p. 101)

participants. When breaking down data into codes/concepts discrete passages of data are taken apart word by word, line by line, sentence by sentence and paragraph by paragraph. Each discrete area of data is then given a name, something representative of the phenomenon to which it refers (Glaser, 1998; Hutchinson, 1988; Strauss & Corbin, 1990; 1998). These code words draw concepts from empirical data and are derived from observations made in the substantive area under study. In line with Glaser's (1978) suggestion questions are asked of the data to reveal codes and concepts. For example, what does the data reveal in the study? What category does an incident indicate? What is actually happening in the data, i.e., what is the basic social-psychological problem facing the participants in each scene?

To reiterate, in open coding data are broken down, examined, compared, conceptualised and categorised and codes or concepts, the salient names given to information disclosed by participants, are applied to data. For example, in one segment of data "I think they know about it [AD/HD] but they don't really help a lot. They might help in some ways but they just probably think I can handle it [problems] my way, move away from it all and all that" (YJ-interview 3 – 532-535) the categories 'seeking space', 'managing conflict', 'protecting' and 'gaining control' were identified.

In Glaser's (1992) opinion, it is important for this area of coding to be well constructed. When the constant comparative method is approached systematically its categories and their properties carefully induced from a substantive area, the theory that emerges will fit, work, be relevant and have modifiability. Moreover, the emergent carefully induced theory, will, not only "fit the realities under study in the eyes of subjects, [but also] practitioners and researchers in the area (Glaser, 1992, p. 15).

In my research, open coding commenced with data collection in July 2001 and concluded November 2002.

Developing categories.

The codes and concepts that emerged in my research through open coding were compared one with the other and linked together through the ongoing constant comparative process. According to Hutchinson (1988), with this higher level of conceptualisation integrates code words and concepts that may now defined as

categories. In other words, where open coding breaks down data into small pieces, this higher level of conceptualisation condenses these small pieces into higher order codes/categories.

Categories are arrived at as abstractions of phenomenon and are discovered when codes/concepts are compared one with another and appear to relate to the same phenomenon (A.L. Strauss & Corbin, 1990). Categories materialise when the researcher asks questions of the data such as those suggested by Iurita (1990, p. 63): "What category does this incident indicate?... What is actually happening in the data?" Some of the Level I or open codes become subsumed during this process, while some codes now become properties or dimensions of categories. Properties, or aspects of a category, are "attributes or characteristics pertaining to a category [while] dimensions are the location of properties along a continuum" (A.L. Strauss & Corbin, 1990, p. 61). Dimensions with their associated properties demarcate or shape the data identified by the researcher. For example, gender is a dimension of the properties male and female. Once a category is developed in terms of its properties and dimensions it may be further differentiated by breaking it down into sub-categories. According to Strauss and Corbin (1998), sub-categories detail a category further in terms of when, where, why and how a phenomenon is likely to eventuate. Sub-categories also have properties and dimensions.

Figure 3, depicts the way in which conceptual categories may be delineated by their dimensions and properties through the conceptual elements of context (the boundary of the inquiry), conditions (the way in which phenomenon shape actions/interactions), process (actions and interactions) and consequences (Kools, McCarthy, Durham, & Robrecht, 1996).

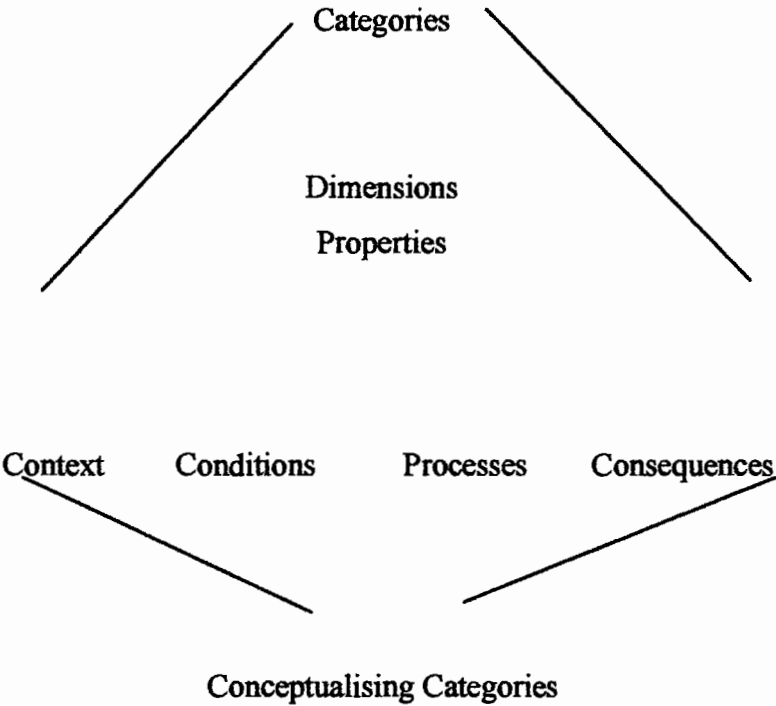


Figure 3. Explanatory matrix ¹¹

Axial Coding

Table 4 presents additional grounded theory terms that are introduced during axial coding.

¹¹ Source: adapted from Kools et al. (1996, p. 319)

Table 4

Glossary of additional terms and meanings employed during grounded theory analysis commencing in the axial coding stage¹².

Terms	Meanings
Causal Conditions	Events, incidents, happenings that lead to the occurrence or development of a phenomenon.
Phenomenon	The central idea, event, happening, incident about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related.
The paradigm	An analytic tool devised to help analysts integrate structure with process.
Structure/Context	The specific set of properties that pertain to a phenomenon; that is, the locations of events or incidents pertaining to a phenomenon along a dimensional range. Context represents the particular set of conditions within which the action/interactional strategies are taken.
Intervening Conditions	The structural conditions bearing on action/interactional strategies that pertain to a phenomenon. They facilitate or constrain the strategies taken with a specific context.
Process	Sequences of action/interaction pertaining to a phenomenon as they evolve over time.

¹² Source: Strauss and Corbin (1990, p. 61; 1998, p. 101)

The theoretical constructs or codes that emerge through axial coding (A.L. Strauss & Corbin, 1990) have their foundations in a combination of the researcher's scholarly knowledge and research knowledge of the substantive field or area being researched (Hutchinson, 1988). These codes emerge as the pieces of the puzzle begin to fit together. The emergent codes weave the fractured story back together to turn concepts back to an organised whole theory and furnish research with the models for theory generation (Glaser, 1998). According to Glaser (1998), theoretical codes in essence conceptualise how the categories and properties of the theory relate as interrelated multivariate hypotheses that account for and resolve the main concern.

In axial coding categories (phenomenon) may be further fractured into subcategories. These subcategories specify a category further in terms of when, where, why and how a phenomenon is likely to occur. In effect, subcategories answer questions about a category in terms of the conditions that "give rise to it; the context (its specific set of properties) in which it is embedded; the action/interactional strategies by which it is handled, managed, carried out; and the consequences of those strategies" (Strauss & Corbin, 1990, p. 97). Subcategories also have properties and dimensions.

According to Strauss and Corbin (1990), this systematic way of relating to data is executed by means of the paradigm, where paradigm seeks to establish the patterns underlying a theory. In Strauss and Corbin's (1998) view the link between categories can be subtle and implicit. Paradigm furnishes research with a scheme that can be used to sort out and organise the emerging connections. Glaser (1978) did not use the term paradigm, but essentially, his list of 18 families of theoretical codes posit the same intrinsic position. These theoretical codes of Glaser's are terms used in standard scientific language. They enable researchers to have greater flexibility when asking questions about their data and the categories in the data. The coding families and the words within these families that were deemed appropriate to this study were identified from those in Glaser's (1978) list of 18 families. They are:

The Six C's – causes, contexts, contingencies, consequences, covariances, and conditions; *Processes* – stages, staging, phases, progressions, etcetera; *The Degree Family*: Limit, range, intensity, extent, amount, level, extreme and the like; *The Dimension Family*:

Dimensions, elements, divisions properties of, intensity, aspect: *The Strategy Family*: Strategies, tactics, managed, maneuverings [sic] etc; *The Interactive Family*: Reciprocity, interdependence, dependence and so on; *The Identity-Self family*: Self-image, self-concept, self-evaluation, identity, self-realization. Finally the *Mainline Family*: social control, socialization. (p. 74-77)

According to Irurita (1990, p. 64), families of theoretical codes, such as those of Glaser, allow the researcher to further ask questions of the data such as: "What is this behaviour a result of? On what did this behaviour depend? What were the consequences of the action/behaviour? What strategies or prerequisites were required to achieve certain outcomes? What stages or processes occurred to facilitate these outcomes?" In my research, questions such as these led to incidents being further compared, memos being written and further questions, ideas and hypotheses explored. Data garnered from these questions directed additional data collection and hypothesis testing. This constant comparative method results in categories being raised to more abstract levels, category links and relationships identified and integrated and selective coding commencing. This constant movement between inductive and deductive thinking, this "back and forth movement, is what makes our theory grounded!" (Strauss & Corbin, 1990, p. 111).

Selective coding that follows axial coding facilitates the emergence of the core variable or category (Strauss & Corbin, 1990). The core category is the abstract name given to the central phenomenon around which the other categories revolve (Strauss & Corbin, 1990).

Prior to outlining the process of selective coding, it would seem appropriate to discuss memo writing and diagramming that are ongoing processes throughout the data analysis in grounded theory research.

Memo Writing

Throughout my research, memos were written and diagrams constructed. These memos and diagrams, which are designed to capture ideas and document recurrent themes observed in the data (Chenitz & Swanson, 1986) were kept either in a separate notebook or in the memo section of QSR NUD*IST N4. The line number and

code appropriate to each data segment being noted with each memo. These memos alluded to thoughts and ideas about codes, categories and theoretical constructs and the relationships between the categories and their properties. As each new code evolved it was stored in the QSR NUD*IST N4 index tree as a node and, where indicated, a memo was attached. According to Strauss and Corbin (1990, p. 240), initial code memos may "be sparse and come up with few conceptual labels". Nevertheless with time as thoughts and ideas evolve and questions continue to be asked, categories and their dimensions and properties are linked and the code memos take greater form.

The primary objective of the grounded theory method is the generation of substantive theory. This is attained through descriptive passages recorded as memos. Memos are the researcher's deliberations over concepts and categories garnered from careful, systematic data collection. This deliberation serves to raise categories to higher conceptual levels. Memos draw out theoretical coding and the properties of substantive codes which are the categories and properties of the theory and enable the researcher to fill out the descriptive data (Glaser, 1978). Memos allow for the story to emerge. Grouping memos according to schemata permits each scheme to be sorted and then presented. Following are two examples of memos referring to the same code (category). These two memos were written at different times during my data analysis. The first is a general memo written after the first series of interviews while the second memo was written at a later stage in the analysis process. These two memos demonstrate how conceptual understanding of a category developed over time and how the category and its properties and dimensions were related to other categories within the process.

June 2002 General code note

Losing control: this is associated with the problem of Being Treated Differently. But is it part of process or affiliated with the problem? I can hypothesise that losing control, is disempowering and may be a result of prejudice that is related to discrimination, they are all part of the main problem Being Treated Differently. The process that appears to be the one adopted by the adolescents is one that intends to overcome this.

The loss of control can be complete or only partial. How they react will depend on the perception of loss of control coupled with their social experience.

This needs to be reviewed in the context of the social perception of other, Personal construct theory and symbolic interactionism.

As a general code note employed in my research, the tone of this memo was exploratory. It allowed me to formulate thoughts and indicate where questions needed to be asked of data. The theoretical memo that follows shows the way in which my thinking became more delineated as analysis of data progressed. Specific concepts that evolved from thoughts and questions relating to the data and a pattern of process then began to emerge.

October 2002 Axial/Theoretical Memo

Causal condition: Losing control

Phenomenon: Balancing

Properties of losing control: Losing control has two aspects a) losing control of self - like crying in front of others and b) losing control because others have 'dobbed you in' and 'let out you are ADHD' i.e., Being Treated Differently or discrimination.

Specific dimensions and strategy for Balancing: The degree of loss of control is relative to the importance of each incident in relation to how one sees oneself *developing insight*. Loss of control through being dobbed in will lead to *fortressing* (a protective strategy) being increased and withdrawal from the situation.

Comments and consequences: Losing control is a causal condition of *Balancing*.

Further action: This needs also to be looked at via documents as to whether all those who experience disabling environments look at them in the same way.

Diagram Construction

An example of a diagram constructed early in the study in March 2002 may be found in Figure 4. Diagrams are another way of conceptualising ideas and capturing thoughts as visual representations of an analytical scheme. The Diagrams may represent a whole or a part of the scheme. According to Strauss and Corbin (1998, p. 237) "memos and diagrams mirror the depth and complexity of thought of the evolving theory". They are particularly useful, according to Chenitz and Swanson (1986), to the analyst when they are overwhelmed with memos and need an overview or picture of the analysis. The act of diagramming allows a researcher to "finalise relationships and discover breaks in logic" (A. L. Strauss & Corbin, 1998, p. 238). Figure 4 illustrates the way in which my thoughts were developing. This diagram also assisted me to clarify thoughts, ideas and concepts. Diagrams such as this were initially drawn using Microsoft WORD software, but later *Inspiration @ 7* (*Inspiration version 7: Getting started, 2002*) became the ideal software tool for the diagrammatic depiction of data.

BASIC SOCIAL PSYCHOLOGICAL PROCESS: FORTRESSING

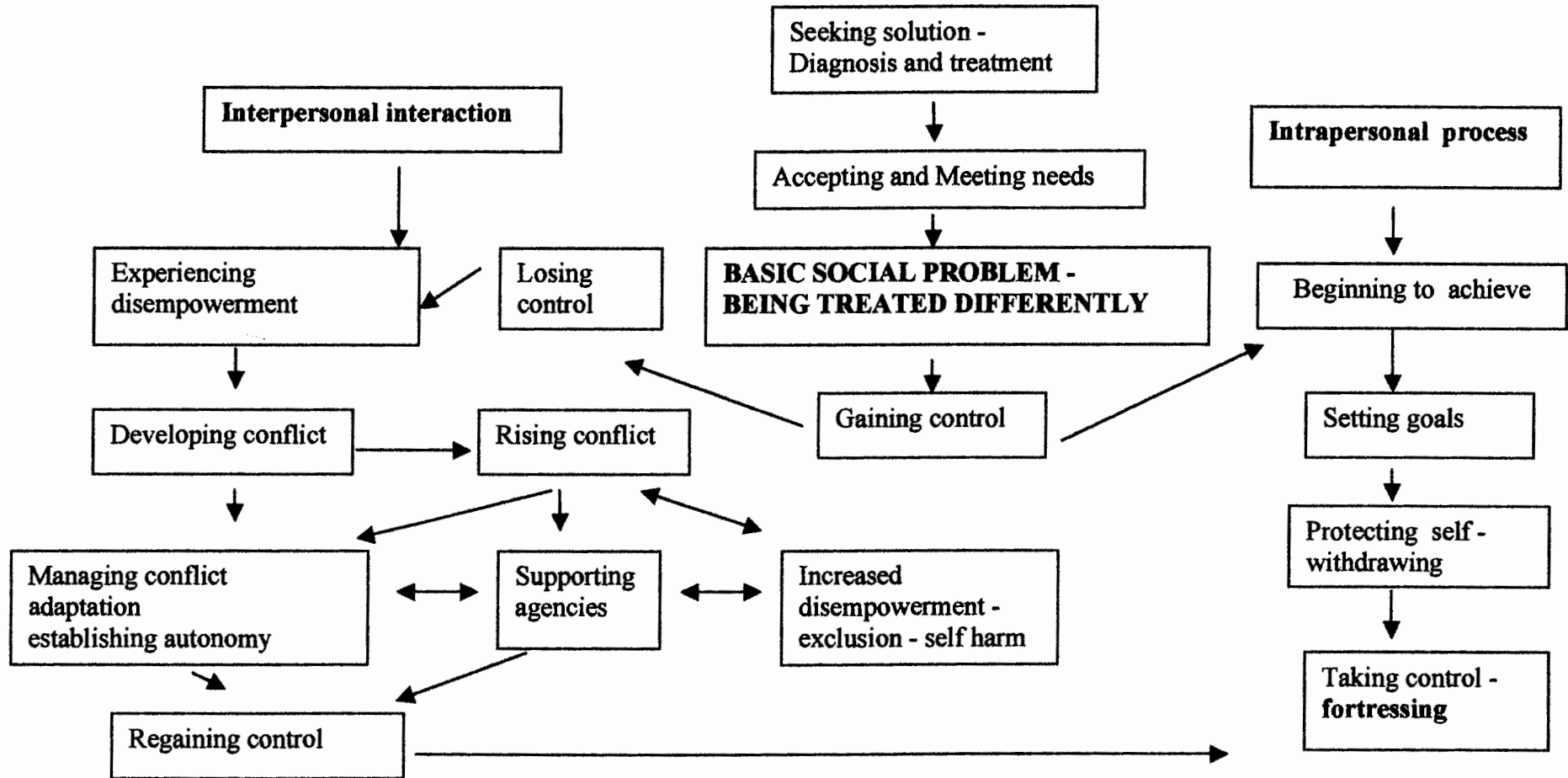


Figure 4. October 2002 - A theoretical diagram depicting process

Selective Coding

A glossary of additional terms that were applied during selective coding is presented in Table 5 that follows.

Table 5

Additional terms and meanings employed in grounded theory analysis that are introduced during the selective coding phase¹³.

Terms	Meanings
Story	A descriptive narrative about the central phenomenon of the study.
Story Line	The conceptualization of the story. This is the core category.
Selective Coding	The process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development.
Core Category	The central phenomenon around which all the other categories are integrated.

As data collection and analysis progressed, I was faced with the task of collating the categories that emerged from open and axial coding to form the framework for the substantive theory.

This aspect - making it all come together - is one of the most difficult things of all... Quite apart from actually achieving it, it is hard to inject the right mix of (a) faith that it can and will be achieved; (b) recognition that it has to be worked at, and isn't based on romantic inspiration; (c) that it isn't like a solution to a puzzle or

¹³ Source: Strauss and Corbin (1990, p. 117).

a math problem, but has to be created, (d) that you can't always pack everything into one version, and that any one project could yield several different ways of bringing it together. (A.L. Strauss & Corbin, 1990. p. 119)

Selective coding is the process of sorting data to allow the 'core category' (variable), which spells out most of the behavioural variation to emerge from the data. As the last stage in grounded theory process the task of selective coding is to progress data to a higher more conceptually abstract level. With the emergence of the 'core category' selective coding becomes a delimiting process with the researcher now selecting only codes that relate to the 'core category' that has been discovered in the data. For a category to be accorded the role of 'core category' it must occur frequently in the data, link data together and account for data variations (Hutchinson, 1988). In my research selective coding and sorting commenced in July 2002 following the preliminary stages of open and axial coding, as well as the processes of memoing and diagramming.

The grounded theory perspective assumes that those who share common circumstances will share the same "social psychological 'problems' that are not necessarily articulated or conscious but grow out of their shared life" (Hutchinson, 1988, p. 113). In order to resolve the 'problem' a basic social process or a 'core variable' (also known as a core category) is developed. According to Glaser (1978), this core category can be any kind of theoretical code: a process, a condition, two dimensions, a consequence and so forth. In Glaser's (1978, p. 100) opinion, basic social processes are "*pervasive [his italics]* since they are fundamental, patterned processes in the organization of social behaviors which occur over time and go on irrespective of the conditional variation of place". Basic social processes are robust and account for change over time, facilitate ease of meaning, fit and have workability. Process by its nomenclature, however, indicates temporariness basic social processes, therefore, focus on "patterned lines of conduct as they occur over time under different conditions which generate stability, and variability" (Glaser, 1978, p. 102). For a core category to be identified as a basic social process:

Something occurs over time and involves changes over time. These changes over time ordinarily have discernable [*sic*] breaking points – discernable [*sic*] to the extent that stages can be perceived, as theoretical units in themselves with condition, consequences (which may be another stage), other properties, and so forth which are unique in form to each particular stage. (Glaser, 1978, p. 97-98)

In Glaser's (1998) opinion, aside from basic social process there are other basic models of process. Two of these models are basic social-psychological process and basic social structural process. Basic social-psychological processes imply process and are indicated by conceptual level words such as becoming, potentialising, grieving, teaching and learning curves. All people progress through processes such as these as functional requirements of society. Aligned with basic social-psychological process are basic psychological processes these "abound in the self-image family, such as identity development, character formation" (Glaser, 1998, p. 170). Alternatively, basic social structural process, as the name implies, refer to structural conditions that process and that have high impact in the life of an organisation and are routinised, such as shifts in a hospital, semesters or quarters (Glaser, 1978; 1998) Basic structural process such as these have great social psychological consequences according to Glaser (1998). It is Glaser's view that a basic social psychological process and a basic social structural process may merge and, therefore, may occur concurrently.

In order to piece the story presented in my research together selective code note diagrams were developed. An example of a Selective Code Note Diagram is as follows:

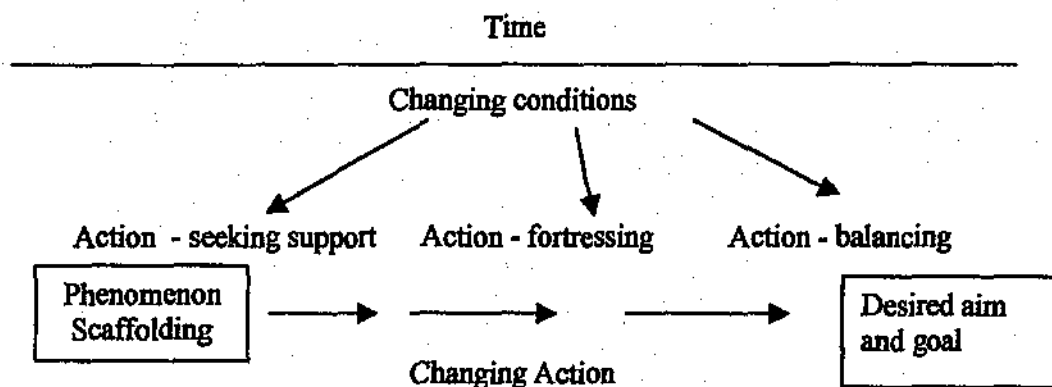


Figure 5. Selective Code Note: Process of achieving aims and goals¹⁴.

It is at this point in the analysis that the main theme or 'story line' will start to become clear. It is from this central theme or 'story line' that the substantive theory emerges to account for how the group resolves the basic social problem. The overarching 'core category' now becomes the focus of the story. The other salient categories that have emerged are then related to this 'core category' as subsidiary categories (A.L. Strauss & Corbin, 1990). The 'core category' and the subsidiary categories explain how the basic social problem was managed and the desired outcomes achieved. Questions similar to those in earlier coding levels are asked of the data in the process of sorting and selective coding and allow the 'story line' to emerge to its full extent. In my research these questions included: What is the basic social problem that the participants have to cope with? What is the basic social process that they use to cope with the problem they experience in the management of their lives? It is questions such as these, in conjunction with further memos and diagrams, that allowed me to transcend the empirical nature of data and to think in theoretical terms and as Strauss and Corbin (1990, p. 144) suggested "to capture process analytically". In my research, as the story line will show, this process was identified as being primarily a basic social-psychological process although, as my data discussion will show, structural processes were later identified that impacted on the basic social-psychological process. The various data, gathered from individual interviews, focus groups, observations and documents were then directed towards discovering concepts and hypotheses.

¹⁴ Source: adapted from Strauss and Corbin (1990, p. 145)

These concepts and hypotheses were then tested, compared and contrasted in each different situation so that the emergent substantive theory related directly to the ever-changing reality of the everyday life of the adolescents with AD/HD.

Theoretical sampling decisions were ongoing throughout the entire grounded theory research process, however, as the basic social-psychological process emerges it serves to direct further deliberative theoretical sampling (Hutchinson, 1988). In this situation theoretical sampling now seeks to gather data so as to enable the saturation of categories and properties in the search for theoretical completeness (Glaser, 1998). This process is continually refined as the substantive theory emerges.

Strauss and Corbin (1990) suggest that this process of integration begins with the researcher writing a few sentences that give a general sense of what the study is all about. In my research this was accomplished by the story outline depicted below in the form of a preliminary Selective Code Note.

September 2002 – Preliminary Selective Code Note – Descriptive Story

My research was made up of over 45 hours of interviewing with adolescents with AD/HD to find out about what they thought about their diagnosis of AD/HD, the use of stimulant medication and how they impacted on their lives, at home, school and socially. What struck me about the interviews was that all the adolescents were determined to manage their lives and get on with achieving their aims and goals. As I got to know them better I came to appreciate the problems they had been having. After they started taking stimulant medication they came to understand why some of these problems existed and what their parents and teachers were 'on about'. They accepted that to take charge of their lives they had to change themselves and fit in. Those who were very shy saw this as a good way of hiding their AD/HD related problems from the world. We talked a great deal about their medication and why they did not like it. They all said that after trial and error they came to the realisation that they needed it. Some of them had real problems

with friends and school and these were very distressing for them and brought new problems for these adolescents. All the adolescents were aware that society thought of them as different and treated them differently and this hurt them. Although, this Being Treated Differently did not deflect the adolescents from wanting to achieve their aims and goals it just made it more difficult. It became apparent towards the end of the research that those with the greatest support from family, friends and school were more likely to achieve their aims and goals than those whose support in these areas was minimal or negative. Those who lacked support from family, friends or school thought of this as a disadvantage and disempowering. At all times, however, the adolescents sought to improve their support mechanisms as they recognised that their support mechanisms helped them to achieve their aims and goals.

This story description formed the basis for developing the fully integrated theory about how a group of adolescents diagnosed with AD/HD and using stimulant medication manage their lives.

The core process that arose from this story represented the main theme of my research. Its power lay in its ability to pull the core category and all other categories together to form an explanatory whole. In my research two near core categories emerged, these near core categories drew the other categories together, yet did not provide an overarching theme. Nonetheless, they did have a significant affect on the storyline as a whole. How the near core categories were discovered in my research is discussed in chapter five.

As with the other levels of coding, I developed further selective and theoretical code notes that became the basis for writing the theory. As these selective code notes were written and sorted they assisted in refining the theory until the process outline fully evolved, capturing as Hutchinson (1988) suggested, the 'breakthrough' in the researcher's thinking and saturation was now reached. It is at this moment, according to Glaser (1978, p. 129), that the theory "freezes the on-going for the moment in a fixed conceptual description". The final selective code note that moved the story from description to conceptualisation will be presented in chapter five. Data saturation occurred when no new conceptual

information became available to indicate new codes or to amplify those codes that already existed. Once all the data were accommodated within the selected theoretical categories and the patterns of meaning and behaviour were established and predictable, then a sense of closure was reached. Nevertheless, as Cutliffe and McKenna (in press) observed, "for qualitative researchers to assert that they have achieved saturation and consequently that they 'know', involves a degree of faith grounded in the empirical confidence they have attained from repeatedly comparing data to additional data" (p. 4). Consequently, as Cutliffe and McKenna suggested, the prudent researcher would be wise to note this "element of *faith*" when writing up their research (p. 4).

As selective and theoretical code notes fill in the gaps in logic in the central theme they become increasingly more theoretically conceptualised. The aim of these theoretical codes notes was to ensure that the theoretical framework of my research had integrity and was able to withstand close inspection. The sorting of these theoretical code notes to ever more abstract levels allows a researcher to "conceptually zero-in" on the data (Glaser, 1978, p. 120) and increases the conceptual density of the theory. Theoretical codes notes or memos written for each level of process, such as the one that follows, formed the basis for writing up the substantive theory that emerged from the data analysis.

The following is an example of a theoretical code note from my research:

Theoretical Memo – October 2002

Processes and properties and dimensions of the category *scaffolding*.

Reaching for the light is a complex theory that encapsulates six distinct categories, the first four represent the process and the last two are the near core categories. (1) *seeking solutions*, (2) *transforming*, (3) *scaffolding*, (4) *potentialising*, (5) *fortressing* and (6) *balancing*. These six interlinked categories each have their own processes and sub-processes.

Scaffolding is an important aspect within the process. Adolescents diagnosed with AD/HD engage in a very complex process in order to manage their lives effectively. *Scaffolding* refers to both the coping skills they develop and the support they seek from family, school and friends. Without *scaffolding* the *fortressing* that surrounds self as a protection against Being Treated Differently (the problem) can be breached. Adolescents with AD/HD who engage in *scaffolding* are on the one hand, endeavouring to overcome their own intrinsic problems associated with the symptoms of AD/HD; to do this they develop specific coping strategies for accommodating their symptoms of AD/HD. On the other hand, they are seeking support from each aspect of their social environment. *Scaffolding* in the school environment depends on *changing attitudes* (a dimension of *school scaffolding*) within the school towards any previous problems experienced by the adolescents. For example: *teacher attitude* (that is an aspect of the dimension *changing attitudes*), refers to how a teacher relates to the adolescent's diagnosis and whether they support they offer to those with AD/HD in the form of accommodating strategies to assist the adolescent to improve work outcomes and raise levels of self-esteem. Positive *teacher attitude* is critical to adolescents with AD/HD. Negative *teacher attitudes* can be very damaging. The family environment furnishes the adolescent with AD/HD the most important *scaffolding* framework. Parents *providing boundaries* and *understanding* are critical aspects of family support. Without effective positive family support, particularly from the parents, the adolescent has a tendency to withdraw into him or herself; *fortressing* is increased. To the adolescent being *scaffolded* by peer/friends is also significant. *Having friends, being cool* and *being included* are all dimensions of the process of *peer scaffolding*. When an adolescent is comfortable within their social group they will elicit their groups' support by letting them know of their problems. When they are not sure of the reaction or anticipate prejudice from a group they will maintain secrecy about their diagnosis.

Summary – Coding

Table 6 summarises the way in which the constant comparative grounded theory method occurred in my research. As with many qualitative studies the data collection and analysis in my research was a dynamic process. Sensitivity and empathy were essential attributes for me in order to maximise insight into the phenomenon being examined i.e., the social experience of adolescents diagnosed with AD/HD and how they manage their lives.

This coding summary brings to a close my discussion on how the coding and analysis process in my research was carried out using the grounded theory method. A summary of the grounded theory method as a whole follows Table 6. Subsequent to that the specific criteria for evaluating grounded theory research that directed my research are outlined.

Table 6

Grounded Theory: The Constant Comparative Method Summarised¹⁵

PROCESS	PRODUCT
Constant comparative method	Open coding – called <i>in vivo</i> or substantive
Constant comparative method	Concepts and code words are subsumed into categories
Constant comparative method	Axial coding – theoretical constructs begin to emerge.
Memoing	Writing of theoretical ideas
Theoretical sampling	Dense data which leads to the illumination and expansion of theoretical constructs
Sorting	To identify the basic social process (BSP) – the central ‘theme’
Selective coding based on BSP	Theory delimited to a few theoretical constructs, their categories and properties. The story line emerges
Saturation of codes, categories and constructs	A dense parsimonious theory covering behavioural variation; a sense of closure
Literature review	Discovering literature that supports, edifies or extends the proposed theory
Writing the theory	A piece of publishable research

Summary: Grounded Theory Method and Procedures

The grounded theory approach to qualitative research was the method employed in my research. As a constructivist, constant comparative approach to

¹⁵ Source: adapted from Hutchinson (1988, p. 139)

methodology, grounded theory accepts that multiple social realities are relative and not absolute, realises that knowledge is mutually exclusive between the observer and the observed and aims toward interpretive comprehension of subjects' meanings. My research focussed on 'how adolescents diagnosed with AD/HD manage their lives'. With this focus, the decision was made to underpin the research framework in the social theory of symbolic interactionism, which is located within the interpretative paradigm. The major sources of data were interviews and focus group studies with seven adolescents diagnosed with AD/HD. Three further participants joined my research as the analysis reached the deliberate theoretical sampling phase.

The grounded theory analysis for my research followed the proscribed route of open, axial and selective coding, theoretical sampling, memoing, diagramming and literature and document searches. Participant observation and telephone conversations, supplemented my data. The codes and categories that emerged during data analysis reflected the meaning of what was happening in my research. Categories and related subcategories were then conceptualised and theoretical constructs were formed. These theoretical constructs were then transformed into a story from which the substantive theory emerged. In my research the substantive theory *Reaching for the Light* which emerged was a complex theory constructed from four categories of process: (1) *seeking solutions*, (2) *transforming*, (3) *scaffolding*, (4) *potentialising* and two near core categories *fortressing* and *balancing*. A substantive theory is a theory in which the core category, categories, sub-categories and concepts and their properties and dimensions may be traced back to the data. The central theme or story from which the substantive theory evolves accounts for how the basic social problem identified by the group is resolved. The grounded theory process culminated with the writing of the report in which the findings were placed in the context of existing theories and relevant literature. QSR NUD*IST 4 software was used to facilitate the management of data and proved most effective for coding, sorting and recalling coded segments and relating memos to the data. Diagrammatic representation of thoughts, ideas, concepts and process was facilitated by the software package *Inspiration* ® 7 (*Inspiration version 7: Getting started*, 2002).

Special Considerations and Limitations

Some of the limitations of my research have already been discussed. With the small number of participants a consideration of paramount importance in my research was keeping attrition as low as possible. As a way of thanking the participants for their involvement and to encourage them to continue in my research, following each interview each participant received a voucher valued at between \$4-\$10¹⁶. These vouchers were greatly appreciated by all the participants some of whom kept them as tokens, or symbols of achievement, rather than using them.

A further consideration was the audiotaping of interviews. Glaser (1998) did not advocate audio taping interviews, rather he discouraged this process. In his view, taping is a waste, as it tends to overwhelm the researcher with a monstrous quantity data that goes far beyond the needs of grounded theory. In my research, however, certain limitations within the interviewing process necessitated my not observing this 'cardinal rule of the sole researcher' (Glaser, 1998). These limitations were two fold first, the disorder AD/HD brings with it memory constraints and, therefore, when talking there was a tendency for the adolescents to interject a totally new thought into their on-going discussion whilst it was 'in their head'. Second, recording detailed observations relating to the actions, mannerisms and cultural nuances observed in the interviews with the adolescents was very time consuming and distracting for myself as well as being a distraction to the participants. Nevertheless, I acknowledge and took account of Glaser's concerns during transcription and data analysis. As I was solely involved with the data collection, transcription and analysis, it was possible where data became repetitive to not transcribe each and every interview in their entirety but to transcribe only that which was relevant and new.

¹⁶ These vouchers were generously donated by Regent Cinemas, Hoyts Cinemas, Chicken Treat, Kentucky Fried Chicken, McDonalds and Video Ezy. All these donors were thanked sincerely for their generosity.

Criteria for Reviewing Grounded Theory

Introduction

In order to ensure good scientific criteria with a visible audit trail for the reader to follow, several avenues were developed within my research process. First, a multi-faceted approach was employed to garner information from adolescents in WA with AD/HD relating to their experience of the disorder, stimulant medication use, the impact these have on home, school and social life and how they manage their lives. This approach, as it suggests, involved the use of differing forms of data collection. For the purposes of this research this was accomplished first: phase one - open-ended face to face conversational interviews; phase two - focus groups; phase three - face-to-face semi-structured interviews. Second, documents and literature relevant to my research were also used to discover data; every effort was made to ensure that data collection was accurate, authentic and represented reality. Third, the data collected from each source was assessed macroscopically and microscopically from both my own viewpoint and that of the participants and documented and revisited where appropriate. All phases were continually compared and analysed in order to encourage objectivity. At the same time, as researcher, I was aware of identifying any anomalies I may encounter in the interviews that could materially affect my research and its results. For instance, during the interviews information obtained (be it on a one to one basis or in group discussions) may tend to be unreliable according to Zetterstromm (1990). To offset this problem questions were repeated in slightly different formats throughout the interviews and group discussions and the answers compared. At the same time, in-depth multiple interviews in themselves incorporate features that enhance generalisability and reproducibility. Moreover, the structure of my research as a series of interviews over a period of time, allowed for each participant to make sense of their experience both for themselves and for me and for previous data to be re-evaluated and thoughts and ideas raised on previous occasions to be clarified.

As Patton (1990, p. 11) observed, however, unlike quantitative research, in which a carefully constructed and executed instrument measures what it is supposed to measure, the generalisability and reliability of "qualitative data depend to a great extent on the methodological skill, sensitivity, and integrity of the

researcher" as the instrument in the research. Chapter three introduced Piantanida and Garman's (1999) criteria for judging qualitative research and noted that they were to become maxim for my research. These criteria do not, however, apply specifically to grounded theory. Chapter four now presents criteria specific to grounded theory. It is my intention that these criteria will be used in conjunction with those of Piantanida and Garman as precept for my research.

The specific criteria for judging grounded theory stem from those of Glaser and Strauss (1967) and from the later works by these two authors. For Glaser they were those published between 1978 and 1998 (1978; 1992; 1998) and for Strauss and Corbin their works published in 1990 and 1998 (1990; 1998).

In Glaser's (1998) view four criteria determine the effectiveness of a grounded theory study. These are:

Does the theory work to explain relevant behavior in the substantive area of the research? Does it have relevance to the people in the substantive field? Does the theory fit the substantive area? Is it readily modifiable as new data emerge? (p. 17)

According to Strauss and Corbin (1998), judgments relating to fit, work, relevance and modifiability are dependent upon and must be substantiated by, a research multi-faceted process and sufficiently rigorous to enable the theory generated to be elaborated upon or tested and the findings grounded in empirical data. Glaser (1998, p.16) argues, however, that justifying and legitimating grounded theory should be regarded as only part of the research action; rather the "proof should be in the product". Hence, although in my research reproducibility and generalisability have been selected as the canons to support my research, they are also there to assist the reader to evaluate the adequacy of the research process and its 'predictive ability', its fit, work, relevance and modifiability.

Reproducibility

On the one hand reproducibility or the extent to which studies can be replicated, is intended to give original findings credibility. In the grounded theory approach it has another significance because "the theory is not being verified as in verification studies, and thus [is] never right or wrong. ... it just gets modified by

new data to compare it to. [But] new data never provides a disproof, just an analytic challenge" (Glaser, 1998, p. 19). In grounded theory modifiability is critical. With modifiability a theory does not miss anything as modification through constant comparison permits everything to be included in a theory. According to Glaser (1998, p. 237), "the theory does not force the data, the theory gets modified by it".

Reproducing exactly a socio-psychologically derived study would not be practicable, insofar as replicating situations that exactly match the conditions encountered in the study would not be possible. Modified inductive analysis, discussed earlier in this chapter, acknowledges that the substantive theory, which emerged from my research, is not inclusive beyond the defined location due to the limitations prevailing in my research. As Strauss and Corbin (1990) suggested, however:

Given the same theoretical perspective of the original researcher and following the same general rules for data gathering and analysis, plus a similar set of conditions, another investigator should be able to come up with the same theoretical explanation about the given phenomenon. (p. 253)

Generalisability

Generalisability on the other hand, depends on the predictive ability of the theory and the 'explanatory power' of the theory as a grounded theory. Generalisability is dependent on the researcher's ability to understand the meanings associated with the social experience in a way that is culturally specific. For generalisability to be secured Strauss and Corbin (1990) suggest that the theory should distinguish the conditions in which specific sets of (inter)action pertaining to a phenomenon occur and specify how these relate to the resulting consequences. A theory may be generalised to other substantive areas by modifying it through constant comparisons with new data for a new substantive area. With attention to the criteria fit, work, relevance and modifiability a theory has 'grab' and fit data without pressure. The 'nowism' of grounded theory permits people reading it to see it now and everywhere. In Glaser's (1998) opinion, it is the 'nowism' that has

imagery power as people can understand the concept and use the notion immediately.

More discussion about fit, work and relevance as criteria in their own right, rather than under the umbrella of generalisability is warranted. Glaser (1998) clearly defined them in the following way:

1. Fit is another word for validity. Does the concept adequately express the pattern in the data that it purports to conceptualize? Fit is continually sharpened by constant comparisons.
2. Workability means do the concepts and the way they are related into hypotheses sufficiently account for how the main concern of participants in a substantive area is continually resolved.
3. Relevance makes the research important, because it deals with the main concerns of the participants involved. To study some thing that interests no one really or just a few academics or funders is probably to focus on non-relevance or even trivia for the participants. Relevance, like good concepts, evoke instant grab. (Glaser, 1998, p. 18)

In concluding this section on research criteria, perhaps the most important objective is that, as Ely (1991, p. 156) argued, from the inception of an idea, to the conclusion of a research project the researcher must "pay, continuous, recursive, and, we dare say, excruciating attention to be[ing] trustworthy". Moreover, as Lincoln and Guba (1985) contended, throughout the research the pursuit is on to make the project credible, produce results that can be trusted and establish findings that are worth paying attention to.

Summary of Criteria

To meet good scientific criteria (generalisability, reproducibility, precision, rigour and verification) the grounded theory methodology was mindfully and accurately applied in the theory development through the constant comparative method of qualitative analysis. Measures were taken to increase the rigour of the

application of the grounded theory method. The criteria guiding my research came from two complimentary perspectives. First, the guiding principles of grounded theory developed by Glaser and Strauss (1967) in their first book and from later work published by these two authors. Second, the criteria for evaluating the 'trustworthiness' of qualitative study detailed by Piantanida and Garman (1999) and discussed in chapter three. These two sets of criteria influenced not only the day-to-day workings, but also the writing up of my research. These two sets of criteria were complimentary because Piantanida and Garman's (1999) criteria furnished the research with generic qualitative criteria with which to assess a study, while those of Glaser, Strauss and Corbin (Glaser, 1992; 1998; Glaser & Strauss, 1967; 1990; Strauss & Corbin, 1998) were specific to grounded theory.

Chapter Four Summary

Chapter four has set out how my research was accomplished. It began by discussing the central research question and how that evolved. Chapter four presented an overview of the grounded theory method. My rationale for choosing the grounded theory method as the data collection and analysis platform and how and why grounded theory is underpinned by the interpretative paradigm and symbolic interactionism were also propounded in this chapter.

The data collection process employed in my research was then discussed, this section detailed the interview questions used and the *Aide Memoire* strategy; a strategy that ensures that participants are able to understand these questions. The chapter continued by discussing when the data were collected, the sampling strategy for enlisting participants and a profile of the research population. Theoretical sampling, the grounded theory procedure and how documents and literature were integrated into my research were also alluded to.

The phases of my research, the interview techniques employed and how observational notes and telephone conversations extended the body of information in my research were discussed. The computer software programmes QSR NUD*IST N4 Classic and *Inspiration* ©7 and their place as tools were also referred to and explained.

Finally, a detailed account of the data coding and analysis procedures from the grounded theory perspective was presented. A glossary of grounded theory

terminology was presented in this section, as well as examples of code notes, memos and diagrams used to clarify my thinking. The grounded theory criteria that will be employed later in this dissertation to evaluate my research were also discussed. Further special considerations and additional limitations that emerged during the data collection and analysis process were also detailed.

A detailed account of the substantive theory that emerged through the data analysis process will now be presented in chapters five, six and seven.

CHAPTER FIVE

Outcomes

Introduction

The purpose of my research was to focus on, explore and conceptualise the social experiences of adolescents diagnosed with AD/HD with regards to their diagnosis and the use of medication and to identify how they are able to manage their lives. The research approach employed was the grounded theory method, a constant comparative method for discovering theory. As chapter four indicated the culmination of a grounded theory study comes when theoretical saturation is reached and a story emerges (Strauss & Corbin, 1990). According to Glaser (1978):

Theoretical completeness implies theoretical coverage as far as the study can take the analyst. Thus, it means that he [*sic*] explains with the fewest possible concepts, and with the greatest possible scope, as much variation as possible in the behavior and problem under study. (p. 125)

Theoretical completeness that in effect signals closure of a grounded theory study is accompanied by personal saturation. Personal saturation occurs when the researcher reaches a point where they consider that no new knowledge is forthcoming relating to the phenomenon under study and the researcher is satisfied that the categories with their dimensions and properties have been fully developed. According to May (1986):

How good the theory is depends on how well the relationships are shown, how often the limits of oppositions are defined, how clearly the categories are described, and how clearly the conditions under which certain interactions occur are specified. (p. 153).

As indicated a grounded theory study culminates when theoretical and saturation is reached and a story emerges that explains the core category or process employed by a group to resolve the basic social problem they are experiencing. (For clarity categories, sub-categories, properties and dimensions are italicised in all discussions throughout chapters five, six and seven). In my research, *Reaching for the Light* as a basic social-psychological process describes the nature of events, actions/interactions and happenings that evolved as a response to the basic social problem *Being Treated Differently*. In the participants' view the way in which they interacted in their world and how they managed their lives depended upon whether, or to what extent, they were *Being Treated Differently*. *Being Treated Differently* was thus seen to be the central problem affecting the participants. That is not to say that the adolescents did not have other problems, such as with their symptoms or their medication, but rather that many of their problems stemmed from *Being Treated Differently*. The substantive theory *Reaching for the Light* that emerged from the data is thus the story of a small group of adolescents and their thoughts about how they manage their lives and how they overcome the problems they experience in their lives.

This theory that emerged from the data is to be presented in this and subsequent chapters. First, chapter five intends to discuss *Being Treated Differently* that is the basic social problem experienced by the adolescents and how this problem emerged during the data analysis process. This basic social problem is shown in Figure 6 as Area 1. Second, this chapter will present the substantive theory *Reaching for the Light* that is shown in Figure 6 as Area 2. In presenting the theory I will explain first how the core category and core process emerged from the data and, thereafter, present the theory in the form of a storyline selective code note. Chapter six will discuss the theory in detail. Finally, this chapter (chapter five) will present a theoretical memo relating to the *Typologies of Support* that emerged during the data analysis as influential supporting areas for the

participants. These typologies of support will be discussed in greater detail in chapter seven. They are shown in Figure 6 as Area 3.

Figure 6 is a diagrammatic presentation of the three areas outlined above that are to be discussed in this and subsequent chapters. In each area of the diagram categories (a concept that stands for a phenomena) appear in a box with the yellow background, for sub-categories (a concept related to a category, giving it further clarification and specification) the box has an orange background, for properties (characteristics of a category or sub-category, the delineation of which defines and gives it meaning) the box has a green background and for dimensions (the range along which general properties of a category vary, giving specification to a category and variation to the theory) the box a blue background. Typologies of support have boxes with a pink background. A full explanation of the terms category, subcategory, property and dimension that are employed in all diagrams and discussions relating to these areas were presented in chapter four in Tables 3,4 and 5.

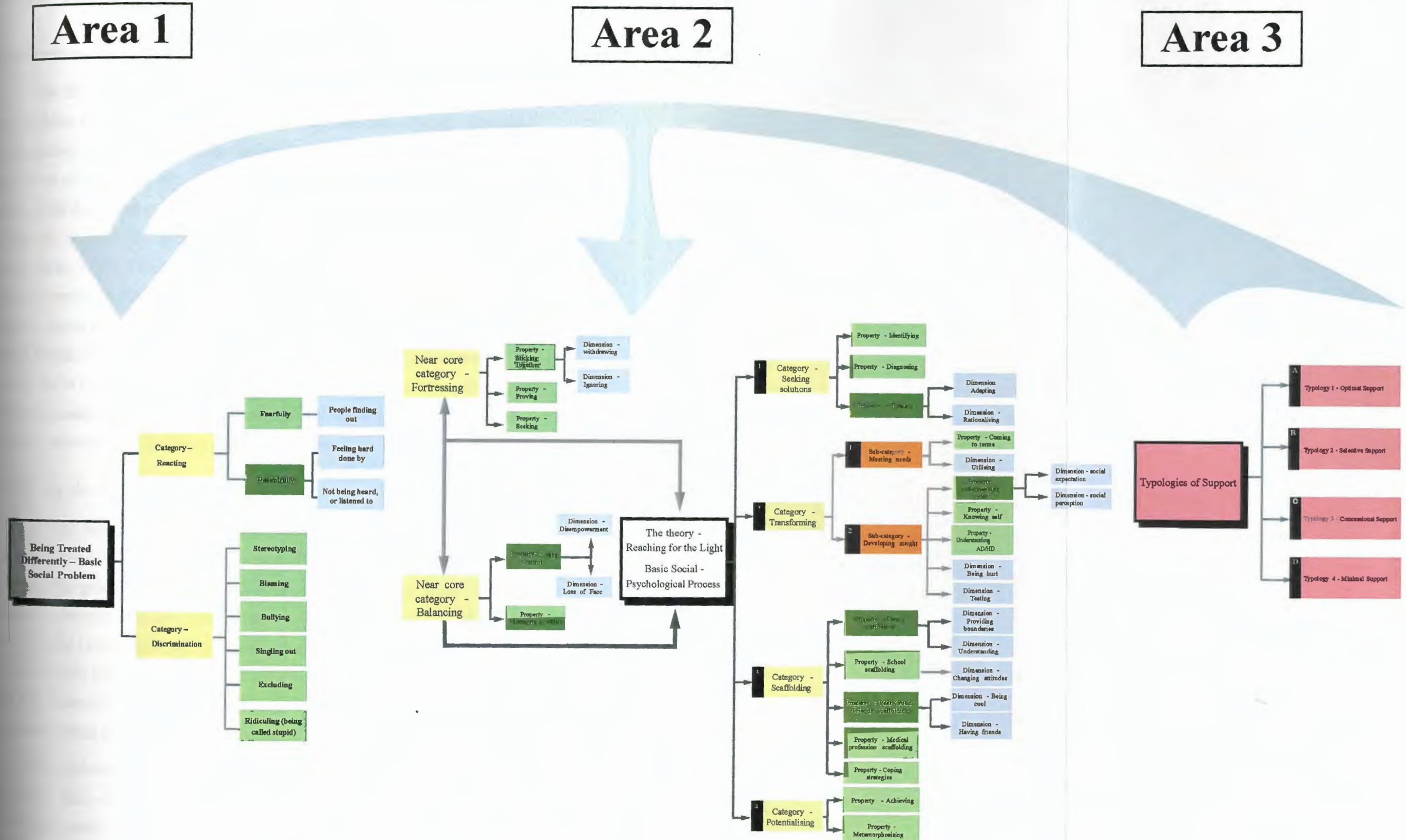


Figure 6: A diagrammatic presentation showing the three areas discussed in chapters two, five, six and seven. Area 1 Basic social problem Being Treated Differently as two categories their properties and dimensions; Area 2 The theory - Reaching for the Light a basic social-psychological process, depicting its categories, sub-categories, properties and dimensions and their properties and dimensions; Area 3 depicting the Typologies of Support that emerged from the data as impacting on areas 1 and 2.

Area 1: The Basic Social Problem: Being Treated Differently

Introduction

The data analysis was initially directed towards discovering the central or basic problem experienced by the adolescents diagnosed with AD/HD. As chapter two explained, AD/HD is a neuro-biological disorder in which significant impairment of executive function is apparent. These impairments are clearly visible in the functional areas associated with sustained attention, inhibition, impulsivity, concentration and hyperactivity (Barkley, 1997a; 1997b; 1997c; Barkley et al., 1997). Those with AD/HD tend to experience low self-esteem, poor academic outcomes and demonstrate risk-taking behaviour. Stimulant medication has been shown to be the single most effective treatment (National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999). A diagnosis of AD/HD and stimulant medication usage per se were not, however, the full extent of the basic problem, but rather adjuncts to the problem as I will now show.

Identifying the Basic Social Problem

A basic social problem is a problem shared, but not necessarily expressed, by a group (Irurita, 1990). As a basic social problem it is the core problem that impacts on the group. The basic social problem articulated by the small group of adolescent participants in my research that was discovered in the data was that of Being Treated Differently. Other problems emerged during the data analysis such as those specific to their disorder. These will be discussed in chapter six. For the most part, however, Being Treated Differently was the problem that the adolescents found to be the most significant.

The adolescents managed their lives in the context of their social experience. Their actions were aimed at trying to ameliorate the problem of Being Treated Differently, to enable them to effectively manage their lives and achieve their aims and goals. Being Treated Differently is first presented as a diagram in Figure 7. A discussion on how the basic social problem was discovered during the data analysis follows.

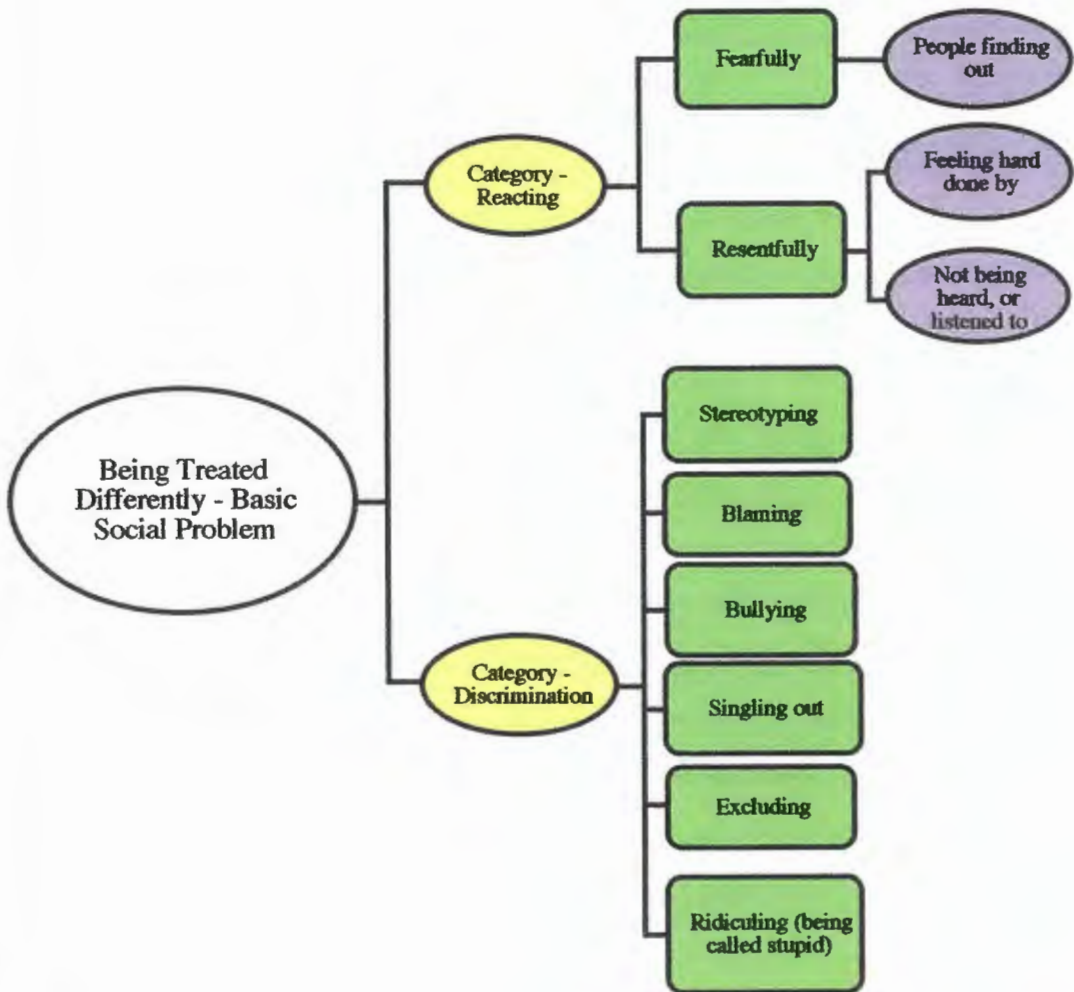


Figure 7. A diagrammatic representation of the basic social problem Being Treated Differently shown as a category with properties and dimensions.

Where segments of interview data are included to illustrate or clarify a category, sub-category, property or dimension they will be referenced with the participant's code, the interview number and the line number. Words that denote categories, sub-categories, properties and dimensions will be italicised to identify them in a discussion.

The basic social problem Being Treated Differently was identified from the data as having two categories; *reacting* and *discrimination*. *Reacting* has two properties that were related to internalised feelings expressed by the adolescents. The two properties of *reacting* were *fearfully* and *resentfully*. The property *fearfully* had a dimension *people finding out*, while the property *resentfully* had two dimensions, *feeling hard done by* and *not being heard or listened to*. These

properties and their dimensions that represent the internalised feelings that were articulated by the adolescents were in-vivo codes.

In the first property *fearfully, people finding out* and the repercussions associated with *people finding out* were articulated by the adolescents in the following way "like talking about me behind my back rumours and things" (BS interview 2: 514) or, "if you said something or someone said something about you and everyone looked at you and laughed" (PB Focus Group 1: 257-265). While another expressed the view that "none of my teachers know I have got ADD. It is only the psychiatrist that knows that I am aware of. If Mum hasn't told anyone else. They treat you differently like, like you are stupid or something" (WK interview 5, 26-55). Another's fear was demonstrated in this statement "well let's see I didn't think my life was worth living cause everyone was treating me like crap" (CB, YJ Focus Group 2, 272-273). Dimensions of the category *reacting* and its properties *fearfully* and *resentfully* varied from minimal to extreme depending on the social experience of an individual.

In the second property *resentfully* in-vivo codes made up the dimensions of the property these included: *feeling hard done by, not being heard or listened to*. An example of dialogue indicating the first code *feeling hard done by* is:

But I could care a shit. It didn't matter what anybody else thought but it mattered when I wasn't invited to other people's birthday parties and no one came to my birthday parties and no one body remembered my birthday. (RA-1, 440-443)

It should be noted at this juncture that where quotations are taken from data they are presented exactly as they were stated in the interview. Changing words such as expletives would, in my opinion, remove emphasis placed there by the adolescent and be inappropriate. Initially, I noted that they tempered their language for my benefit. As my research progressed this deference to me was not as apparent. This language modification is specifically related to cultural expectations. Language deemed appropriate for use between one adolescent and another would not necessarily be considered befitting when an adolescent is conversing with an adult (Jaffe, 1998). As I was trying to mitigate any cultural differences between myself as an adult and the participants as adolescents I made a

point of ignoring bad language as I did not want to deter the adolescents from speaking from the heart.

The second dimension *not being heard or listened to* was observed in the data as follows:

...cause people didn't want to talk about it [problem] really dismissed it. But I actually had a couple of people where I camp with who I keep in touch with and talk it through. Because they go through the same type of thing not being heard no one listening (YJ-FG, 66-69). People not talking to me and having to sit by myself at school really people cheese me off. (YJ-2, 334-335)

The second category of Being Treated Differently was *discrimination*. The adolescents indicated that they considered *discrimination* to be a form of socially perpetrated disempowerment. *Discrimination* was experienced and articulated by the adolescents in all spheres of their social environment; family, school, with peers or friends and from the media. Examples of the in-vivo codes, articulated by the adolescents which formed the properties of the category *discrimination* included: *stereotyping, blaming, bullying, singling out, excluding, ridiculing (being called stupid)*. These properties are articulated in the following extracts:

...[people treat me]...as having a problem a disability they don't like treat me normal. I get called psycho B***¹⁷. (CB-2, 142-158)

Well they treat I am a nothing like I am low life I am worth nothing. I am worth nothing at all. (YJ-4, 401-403)

I don't know it is still something I have a problem with being different. I still have a big problem with that in so many different ways. I don't know why it is bad to be different why does society see being different as a bad thing? When everybody is different everybody is unique. (RA-1, 232-237)

¹⁷ Where a participants name appeared in a direct quotation I have used the First, initial followed by asterisks to ensure anonymity.

The following composite of extracts demonstrate how *bullying* was experienced by some participants. It is interesting to note that the participants who encountered *bullying* were female. *Bullying* was not always physical, in the participants view it more often it took the form of verbal abuse.

Yea difficult 'cos, I got bullied a lot last year so they spread lots of rumours and said "don't be friends with her 'cos she is crap" that's like fine... (YJ-1, 144-4-148); No I don't even know why... whether it was from year eight or what because I got booed a lot in year eight and in year nine no one ever talked to me (YJ-2, 339-340); No not really just verbally. I think they might be scared they would be called a bitch slapper as well. Sort of like ok fine (YJ-3, 572-573); When I went to college for year nine and 10 for about two weeks after I got there to the day that I left I was known as the lesbian. Every day someone would say something to me. People would look at me when I walked passed. People would snicker. Would say shit. It wasn't true. It was just a bunch of year nine girls it was people in the year (RA-1, 453-454)

Discrimination varied from extreme incidents where individuals were totally excluded in certain situations to less overt forms of *discrimination* that left individuals expressing feelings of unhappiness and reacting *resentfully*.

There were positive instances of Being Treated Differently, though the adolescents rarely articulated these occasions. The small number of positive incidents they experienced led to the adolescents considering them to be irrelevant or inconsequential. Those who were fully supported were being more likely than those with minimal support to experience positive reactions from others to their disorder. They did, however, acknowledge that "giving a bit more time" and "explaining tasks more carefully" were ways in which Being Treated Differently may be of benefit at home or in school. Instances such as these were regarded by the adolescents as supportive and quite distinct from the negative implications usually associated with Being Treated Differently.

Being Treated Differently as the basic social problem experienced by the adolescents wove back and forwards through the substantive theory Reaching for the Light. Why individuals were Being Treated Differently and whom or what establishes what was different will be discussed later.

Area 2: The Substantive Theory Discovered from the Data

The ensuing storyline selective code note depicts the sequential processes entered into by the adolescent participants. The theory as a series of sequential and cyclical processes link the (inter)actions undertaken to manage, cope with, or respond to a phenomenon. This phenomenon is the social experience of managing life with a chronic disorder. When an individual has a chronic disorder whose symptoms intrude on their everyday life it has direct implications for how that individual manages their life and constructs self from their perspective and from the perspective of others. The substantive theory that emerged embodied the everyday reality of the substantive area which was the how a small group of male and female adolescents in WA diagnosed with AD/HD, who utilised stimulant medication treatment managed their lives in light of their social experience. It is anticipated that the theory that has emerged from my research will be understood not only by the adolescents with AD/HD but also their parents, doctors and teachers.

Identifying the Core Category and Core Process

The process of discovering the core category came about after several strategies expressed by the adolescents were considered. These strategies emerged from the data as categories and included *seeking solutions* (accommodating the problems inherent in and associated with AD/HD), *adapting* and *transforming* (strategies designed to overcome problems and issues), *scaffolding* (supporting frameworks incorporating coping skills), *potentialising* (achieving aims and goals), *balancing* social interaction and *fortressing* (protecting self). Applying the constant comparative process I, initially, narrowed down the choice to two possible core categories; these were *balancing* and *fortressing*. On further reflection, these categories were not conceptually dense enough to encompass and link together all the data and served to limit the boundaries of any theory that emerged. The two

categories of *balancing* and *fortressing*, however, presented distinct conceptual relationships and interaction with the other categories and the process. They were, therefore, assigned to the roles of near core categories. As the story unfolded it emerged from the data that *potentialising*, seen as the achievement of aims and goals, was the core category towards which all the other categories were directed. I felt, however, that there was yet another level to this story. I now had a core category and three interrelated categories, *seeking solutions*, *transforming* and *scaffolding*. These categories were supported by the near core categories *fortressing* and *balancing*, but the story did not seem complete and I, therefore, returned to the data and to theoretical sampling. As the story building process moved further from description towards conceptualisation the central focus of the data (Reaching for the Light a basic social-psychological process) became apparent; it accounted for the actions, interactions and behaviours encountered in the data, conceptualising and extending the data beyond all other categories.

In order to draw my research to a conclusion I asked questions of the data, along the lines of those suggested by Irurita (1990, p. 67). These were: "What category or process do all other categories seem to be leading up to, which one category seems to be a higher level of abstraction than others? What category or process can others be subsumed under?" The order of categories was changed and reordered to different levels of abstraction until this core process Reaching for the Light became obvious and was identified as the basic social-psychological process adopted by the adolescents with AD/HD. This basic social-psychological process emerged as a two-fold strategy. On the one hand the core process was directed at allowing the adolescents to prove themselves as responsible individuals; on the other hand it was directed at responding to the problems experienced by the adolescents with AD/HD. Reaching for the Light thus accounted for how disadvantage was overcome, life was made equitable and aims and goals (*potentialising*) were accomplished.

Following on from the emergence of the core process and the core category the remaining steps in the analysis, theory development and building of the story were relatively uncomplicated. The categories and their relationships within the overall process that are in line with the thinking of Glaser and Strauss (1967), Glaser (1978; 1998; 2001), Strauss and Corbin (1990; 1998) and Irurita (1990) will

be presented here as a storyline selective code note and then in detail in chapter six.

Prior to commencing the story line some clarification is required particularly in light of the theme of the story line presentation and the adult perception that an AD/HD adolescent's risk-taking behaviour precludes parents from 'letting go of the reins'. The story line presents the social experience of the adolescents and how they manage their lives, but this does not detract from the difficulties they experience as a direct result of their neuro-biological condition. Rather it accords AD/HD its rightful place as a disorder to be appropriately addressed. Moreover, research indicates that for the most part medication enhances the ability of those with AD/HD to focus, maintain attention and inhibit impulsive behaviour (Barkley, 2001b; National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999). With improved levels of concentration, therefore, the adolescent with AD/HD has the ability to moderate behaviour and to develop and introduce strategies to overcome the problems they experience not only with their AD/HD but also with their social environment. Stimulant medication appears to act in much the same way as when a broken arm is stabilised in a plaster, thus allowing the individual to continue to function in their world. Nonetheless, it emerged from the data that how the adolescents managed their lives depended upon four issues:

1. Coping with and addressing the problems inherent in their disorder.
2. Achieving aims and goals.
3. Coping with their social experience.
4. Separate from but interacting with the three issues outlined above were the levels of support available to the adolescents in my research. The adolescents continually sought to address the three earlier issues and manage their lives if, however, an adolescent's level of support from within their social environment was in anyway compromised then it would appear that that adolescent had greater difficulty in managing their life.

The concepts of *manage* and *coping*, as they were applied in my search were discussed in chapter one. The definitions that informed my research being those located in the 2001 Macquarie Dictionary in which *manage* is defined as

"succeeding in one's aims especially against heavy odds" (Delbridge et al., 2001, p. 649). While *cope* is defined so: "to deal effectively or contend successfully with a person or task" (Delbridge et al., 2001, p. 246).

To reiterate, the substantive theory Reaching for the Light was the core process (phenomenon) that emerged from the data and accounted for most of the variations in patterns and behaviours and linked the other categories their processes and sub-processes together. *Potentialising* as the final category in the levels of process was the core category to emerge. *Potentialising* was about achieving aims and goals. It was the adolescents' perception that while they continually sought to Reach for the Light actually Reaching for the Light depended first on them succeeding with their aims and goals (*potentialising*) and second on their level of social support. This core process Reaching for the Light and the core category *potentialising* were recurrent throughout the data. The identification of the core process with its core category guided me in the delimiting process of selective coding of the data and further theoretical sampling (A.L. Strauss & Corbin, 1990).

The story line presented in this dissertation, is a story of hopes, dreams and ambitions, of developing understanding and rationalising relationships in one's world. It is hypothesised that this story, which is presented as the substantive theory Reaching for the Light, may be extrapolated to explain the actions/interactions of many other social groups. But this is a story with a difference, for this is not the story of any social group but rather that of a social minority. At the same time this story has a corollary, the young people who play out this story of Reaching for the Light do so in the face of and in spite of, their experience of social attitudes towards those with AD/HD. Chapters six and seven intend to refer to this point as it relates to the social experience of adolescents diagnosed with AD/HD. For the moment the intention is to present the substantive theory Reaching for the Light in the form of a storyline selective code note. The theory is presented first in diagrammatic form in Figure 8. This diagram is colour coded as before.

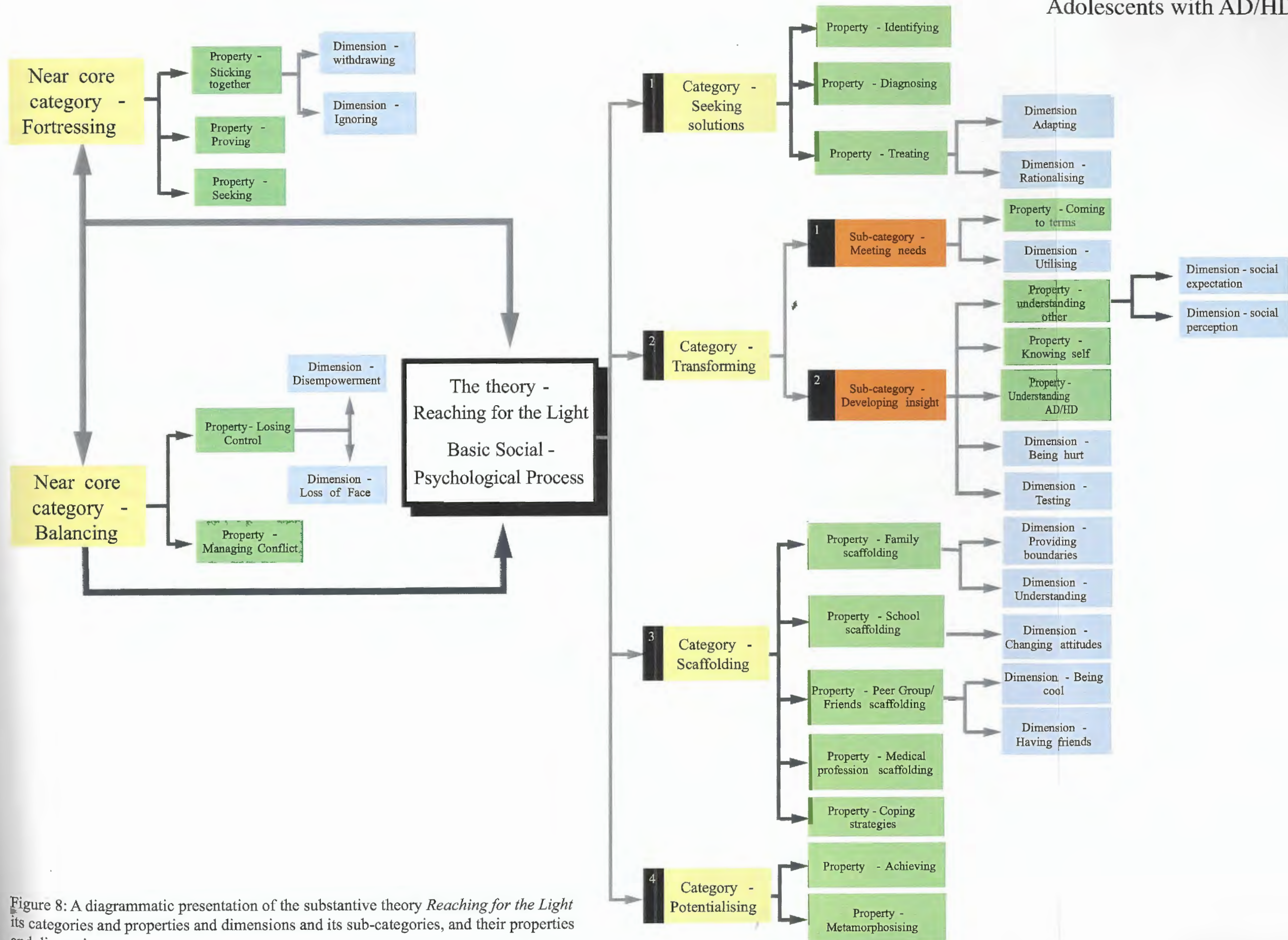


Figure 8: A diagrammatic presentation of the substantive theory *Reaching for the Light* its categories and properties and dimensions and its sub-categories, and their properties and dimensions.

The Storyline

During the final data analysis process the following selective code note as a storyline memo moves the story (shown as a preliminary selective code note in chapter four) from description to conceptualisation. In this storyline and in subsequent chapters the categories of process, their sub-categories (where applicable) and the properties and dimensions that emerged from the data are presented in italics to identify them.

Storyline Selective Code Note: November 2002

The main story seems to be about how a group of adolescents diagnosed with AD/HD who receive stimulant medication treatment manage their lives. The disorder AD/HD creates significant functional problems for the adolescents. Stimulant medication assists them to overcome these functional deficits so that they can begin to take charge of and manage their lives. The social experience of being AD/HD, however, impacts widely on the adolescents and how well they will succeed in managing their lives. For an adolescent to consider that they are managing their life they need to perceive that they are reaching what they regard as their main aims and goals (their *potential*) at any given moment. *Achieving* these desired outcomes is the primary motivating force for these adolescents with AD/HD. To achieve their *potential* an adolescent first has to identify their inherent problems such as poor concentration, lack of focus and poor organisation and poor educational outcomes and *seek solutions* for these difficulties such as visiting a doctor. Following diagnosis the adolescent is more than likely to be offered stimulant medication as a form of treatment. A period of *adapting* to stimulant medication use then follows and they begin to appreciate how stimulant medication alleviates some of their problems and *meets their needs*. The adolescent also comes to appreciate that their diagnosis and stimulant medication use brings with it social problems in that they may now perceive that they are Being Treated Differently. With this knowledge in mind

the adolescent commences the process of managing their lives by *transforming* themselves. This process of *transforming* is two-fold, first, the adolescent develops a greater insight about themselves and their diagnosis; second, they start to engage with their medication and become aware of the benefits and negative aspects of the medication. *Developing insight* is all about comprehending how they themselves operate their strengths and their weaknesses and also what society expects of them. *Scaffolding* (supporting frameworks) by their family, friends and school is critical to the adolescent with AD/HD. Should anyone of these supporting agencies fail an adolescent they are likely to be deflected from their chosen pathway and, therefore, hindered from achieving their aims and goals. Nevertheless, it would appear that an adolescent does not sit passively by when they believe they are either not receiving necessary support or are being actively disadvantaged by the lack of support. Rather, the adolescent will protect himself or herself (*fortressing*) and put in place coping strategies (*scaffolding and balancing*) to overcome the difficulties they are currently experiencing. Lack of support or, the perception that they are being disadvantaged seems to have a bearing on an adolescent's level of self-esteem and this tends to create further problems. When an adolescent perceives the problems they are experiencing are too hard to address at present they will tend to retreat further into themselves (*fortressing*) to sort out what to do and a period of *balancing* will occur. At this point in time that the adolescent will try and develop better supporting mechanisms (*scaffolding*). Instigating coping strategies allows the adolescent to re-evaluate how to manage their life before once more trying to move forward to their aims and goals thus *potentialising* themselves. As they move through the process the adolescent builds on the knowledge they have acquired about themselves, their disorder and the others in their world so they are able them to manage their own lives. This process of overcoming problems and endeavouring to achieve their aims and goals is conceptualised as Reaching for the Light.

Reaching for the Light which emerged as the core process, is a complex theory constructed of four distinct categories that determine levels of process in the quest for Reaching for the Light these are: (1) *seeking solutions*, (2) *transforming*, (3) *scaffolding* (4) and *potentialising*. In addition two near-core categories, '*fortressing*' and '*balancing*', act as process mediators.

As previously discussed the adolescents articulated that for the most part their social experience was one of Being Treated Differently. In their eyes social attitudes towards them were determined by society and its attitude towards AD/HD and the use of stimulant medication treatment. How and whom, treated the adolescents differently determined the way in which he/she was able to utilise this basic social-psychological process Reaching for the Light to manage their lives and the degree and dimensions of process that were required as they were Reaching for the Light. It emerged from the data that an adolescent's ability to manage their life and Reach for the Light was influenced by the level of support available to each individual from within their social environment, family, school and peers/friends.

Area 3: Typologies of Support

During the final coding and analysis process as the selective codes notes and theoretical memos were collated a typology of supporting structures began to emerge that influenced the way in which the adolescents were able to manage their lives and Reach for the Light. The grounded typology of support (Chalmers, 1998; Glaser, 2001; May, 1986) that evolved from my research describes and explains the types of support structure available to adolescents diagnosed with AD/HD as they manage their lives while Reaching for the Light. For the adolescent these typologies are structural functional requirements that form the supporting element of third stage in the process referred to as the category *scaffolding*. It emerged from the data analysis that all the other categories are dependent upon the level of support available to the adolescent participants. The level of support available to each individual determined not only how effectively they were able to manage their lives and continue Reaching for the Light, but also outcomes associated with self-esteem, risk taking behaviour and achievement. These Typologies of Support

that are introduced in the following theoretical memo will be discussed in detail in chapter seven.

Four distinct typologies were identified within the data. These were: Typology 1 - optimal support, Typology two -selective support, Typology three - concessional support and Typology four - minimal support.

Theoretical Memo: December 2002

Adolescents with AD/HD who participated in my research encountered one of four functional structural levels of support.

Typology One: fully supported. The adolescent experiencing this level of support from family, friends and school was more likely to achieve their aims and goals with a minimum of difficulty.

Typology Two: selectively supported. In this typology the adolescent was likely to have the support of their family and friends but not their school. To overcome the problems experienced at school the adolescent adopted protective strategies to balance their lives in order to achieve their aims and goals.

Typology Three: concessional support. In this typology the adolescent tended to receive only negative feedback from the majority of their friends/peers and at school. They continued to be supported by their family, however, and on occasion other agencies. Adolescents experiencing this degree of negativity in their lives, even allowing for the support they did receive, felt increasingly threatened and tended to retreat from contact with their social environment. Moreover, the adolescents with Type 3 support demonstrated a tendency to low-self esteem and depression. Despite this tendency to low self-esteem these adolescents continued to try to achieve their aims and goals and Reach for the light.

Typology Four: minimally supported. This typology presented the adolescent with the least supportive environment. Conflict with family and friends became a feature of their lives and the adolescent tended to believe they are not wanted. The adolescent with AD/HD in my research who was minimally supported appeared to seek out many avenues to achieve aims and goals including leaving home. It emerged from the data that without supporting frameworks adolescents tended to suspend the basic social psychological process Reaching for the Light while they sought solutions to their social problems and try out new coping strategies.

Summary

It appeared that a group of adolescents diagnosed with AD/HD in WA (both male and female) who were being treated with stimulant medication manage their lives through an overarching social-psychological process. Through the rigorous application of the constant comparative method of data analysis I identified four levels of process culminating in the core category *potentialising* that led to the core process of Reaching for the Light. The story line gives an overview of the interrelated social processes that were identified and the stages that the adolescents diagnosed with AD/HD, who utilise stimulant medication as treatment, pass through that enabled them to manage their lives.

The process of Reaching for the Light occurred in both a sequential and cyclical manner. In other words although the adolescents with AD/HD moved through the process in a step by step way from one to two to three etc. they also moved back and forwards through the levels of process as they sought to achieve their aims and goals. The ways in which these steps were made was often directed by outside happenings in the adolescents' world. There were four categories that determined levels of process in the quest for Reaching for the Light these were, *seeking solutions*, *transforming*, *scaffolding* and the core category *potentialising*. If the general sequential progress of the process was impeded the two near core categories of *fortressing* and *balancing* entered the process. These two categories acted as mediators or facilitators of pernicious action and interaction within the process. The amelioration of problems being experienced by the adolescents then

permitted them to continue the process. The adolescents made judgements about how to manage their lives in relation to how far they had been able to achieve their aims and goals – *potentialising*. When they were faced with challenges to the general sequential progression of managing their lives adolescents engaged in actions and interactions which were indicative of the two near core categories. The theory Reaching for the Light will be discussed more fully in chapter six.

The general process of managing one's life and achieving aims and goals such as becoming a student, an employee, or a patient with a disorder such as diabetes may be analysed by the theoretical model discovered in my research, with appropriate variations. The extent to which an adolescent with AD/HD was able to Reach for the Light appeared to vary in line with their social experience.

A grounded Typology of Support emerged from the data analysis to account for the level of outside support that each adolescent experienced from his or her family, school and social environment. It emerged from the data analysis that how well the adolescents were able to manage their lives was determined not only by their own coping skills and ability to achieve their aims and goals but also by the level and effectiveness of outside support available to each one of them.

The relevance of the grounded theory approach for my research was that first, grounded theory makes its greatest contribution in areas in which little research has been done; second, grounded theory concentrates on the discovery of concepts, hypotheses and theories rather than being a research vehicle for theory verification (Punch, 1998).

The following chapters will discuss the outcomes of my research in detail. Chapter six will detail the interrelated basic social-psychological process Reaching for the Light. Chapter seven will discuss the Typologies of Support that emerged from the data analysis in the context of the following hypothesis: members of social groups depend on each other for support to succeed. Chapter eight will present the final outcomes of my research and testable hypotheses that may be drawn from this substantive theory that form a basis for further research in this area¹⁸.

¹⁸ The way in which chapters four and five are presented originate in the theses of Chalmers (1998) unpublished doctoral thesis, University of Western Australia, Perth and Irurita (1990), unpublished doctoral thesis, University of Western Australia, Perth. The clarity of presentation of these theses assisted me in the development of these two chapters.

CHAPTER SIX

Discussion

Introduction

The previous chapter presented a discussion of the basic social problem Being Treated Differently and an overview of the main story Reaching for the Light, which was the substantive theory that emerged from the data and represented the way in which a group of WA adolescents diagnosed with AD/HD manage their lives in light of their social experience. A brief synopsis of the Typologies of Support that emerged from the data was also presented.

The intention of chapter six is to present a detailed discussion of the substantive theory Reaching for the Light. Each category of the basic social-psychological process will be presented individually so that the reader is able to track the integration of the conceptual categories one with another. The theoretical codes that contribute to understanding this substantive theory are woven into each category to demonstrate how they emerged and contributed to that category. Where it is applicable direct quotations from participants, documents and literature will be included and reference will be made to social theories and social understanding of adolescent development and the disorder AD/HD. Where direct quotations from the data are included they will be used to communicate and illustrate the categories, sub-categories, properties and dimensions of the categories that form the levels of process. When interview data are the basis for these texts they will be shown as direct quotations from specific interviews. Each segment will be coded and identified as the words of one specific participant. For example, all passages coded RB refers to one specific participant. The coding format will be the participant's code name, the applicable interview number and text line number.

As chapter five explained the series of interrelated processes which have been discovered to be the way in which this group of adolescents with AD/HD manage their lives in light of their social experience were: *seeking solutions*, *transforming*, *scaffolding* and the core category *potentialising*, with two near core categories *balancing* and *fortressing*.

During the data analysis it became apparent that how an individual with a disorder such as AD/HD manages their life depended on how they constructed and managed self in light of their disorder and its treatment, how they perceived their disorder and how society viewed them and their disorder. The discussion that follows documents the processes that occurred as adolescents who have throughout their lives experienced certain symptoms began the process of *seeking solutions* to these symptoms. Thereafter, following diagnosis of AD/HD and the commencement of stimulant medication treatment the process became one of *transforming* (shaping identity) themselves to meet social mores, values and expectations (the socialisation process) as they sought to achieve their aims and goals (*potentialising*) in order to manage their lives.

The general process of how adolescents with AD/HD *transform* and *potentialise* themselves in order to manage their lives is discussed in this analysis as a series of sequential and cyclical processes in which self is constructed in light of sociohistorical-psychological knowledge (Vygotsky's theory cited in Ratner, 1991), Blumer's (1969) symbolic interactionist perspective on the construction of self and the socialisation process.

My emphasis on managing self, developed once the participants made it clear to me that following their diagnosis and commencing usage of stimulant medication they realised they had to reconstruct themselves (manage self) if they were to *potentialise* and manage their lives. At this point I began to code material for *transforming* – shaping identity. Simultaneously, it emerged that two of my participants were having experiences within their social environment that resulted in them questioning the value of their lives. Their depictions of these experiences gave dramatic insights as to how significant support networks, conceptualised in my research as *scaffolding* and Typologies of Support, are for those with AD/HD. The data also demonstrated that additional mediating processes of *balancing* and *fortressing* were required to overcome some problems, particularly when

scaffolding and support from the family, school friends and peers were less than propitious.

This discussion of the substantive theory Reaching for the Light that emerged from the data will commence by explaining how the near core categories *fortressing* and *balancing* react and interact with the levels of process. For clarity each category of process, its sub-categories (where applicable), properties and dimensions will be discussed individually. Each discussion will be preceded by a diagrammatic representation of the category, its sub-categories (if applicable), its properties and dimensions. In each diagram the category (a concept that stands for a phenomena)¹⁹, sub-categories (concepts that pertain to a category, giving it further clarification and specification), properties (characteristics of a category, the delineation of which defines and gives it meaning) and dimensions (the range along which general properties of a category vary, giving specification to a category and variation to the theory) is colour coded in the same way as Figures 6, 7 and 8.

Figure 8, which is a diagrammatic representation of the theory Reaching for the Light is presented again for the convenience of the reader. This diagram is colour coded as previously with the categories – yellow; sub-categories – orange; properties – green and dimensions – blue. This diagram shows each of the categories with their sub-categories (if that is applicable) and the properties and dimensions in the levels of process that lead to the core process which is the substantive theory.

¹⁹ Source of definitions is Strauss and Corbin (1990; 1998)

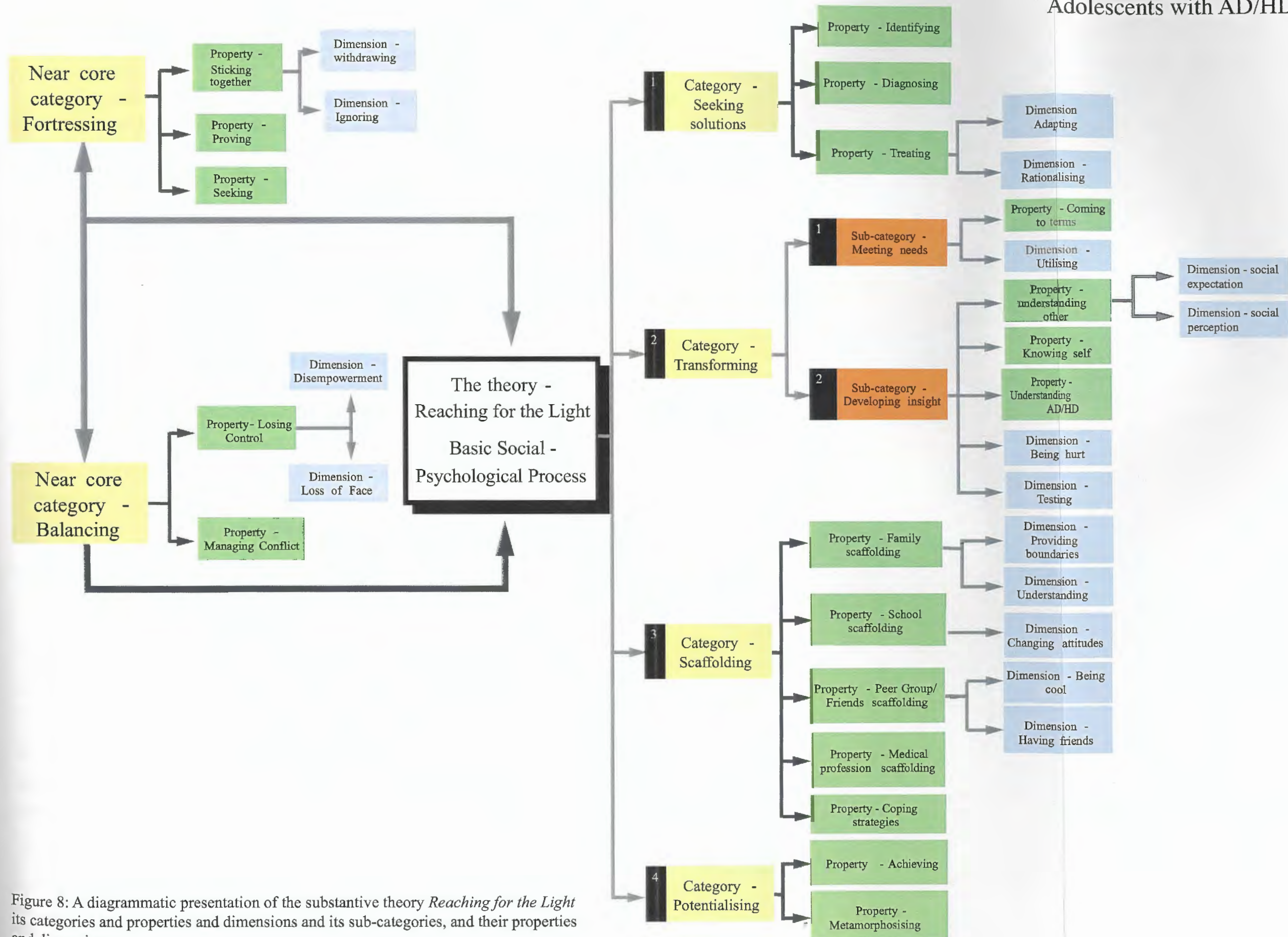


Figure 8: A diagrammatic presentation of the substantive theory *Reaching for the Light* its categories and properties and dimensions and its sub-categories, and their properties and dimensions.

Discussion on the Levels of Process that Lead to the Core Process: Reaching for the Light

The social experience of the adolescents with AD/HD who participated in my research was dominated by the major problem they experienced, which was Being Treated Differently. How the adolescents reacted to this problem when Reaching for the Light and how the problem related to and influenced the levels of process and how the near core categories of *fortressing* and *balancing* acted on the process to overcome the basic problem, are portrayed in the following discussion.

For those with AD/HD managing life is about managing self and the social experience of one's world. In order for the sample group of adolescents to consider they were managing their lives they had to overcome the problem Being Treated Differently and cope with other issues and problems along the way. To overcome the various problems they experienced required differing strategies, some of these strategies were integrated in the levels of process but when the problem Being Treated Differently led to what the adolescent participants considered were extreme pressures they instigated the near core categories. Within these near core categories of *fortressing* and *balancing* were further strategies that contributed to how adolescents with AD/HD sought to manage their lives and Reach for the Light.

Extracts from participant interviews are included to demonstrate how the categories and their properties developed. Each extract is coded to maintain anonymity.

Near Core Category One: Fortressing

Fortressing, rather than being a category within the level of process of Reaching for the Light, stands outside, but interacts with the levels of process as a near core category. How *fortressing* emerged as a near core category was discussed in chapter five.

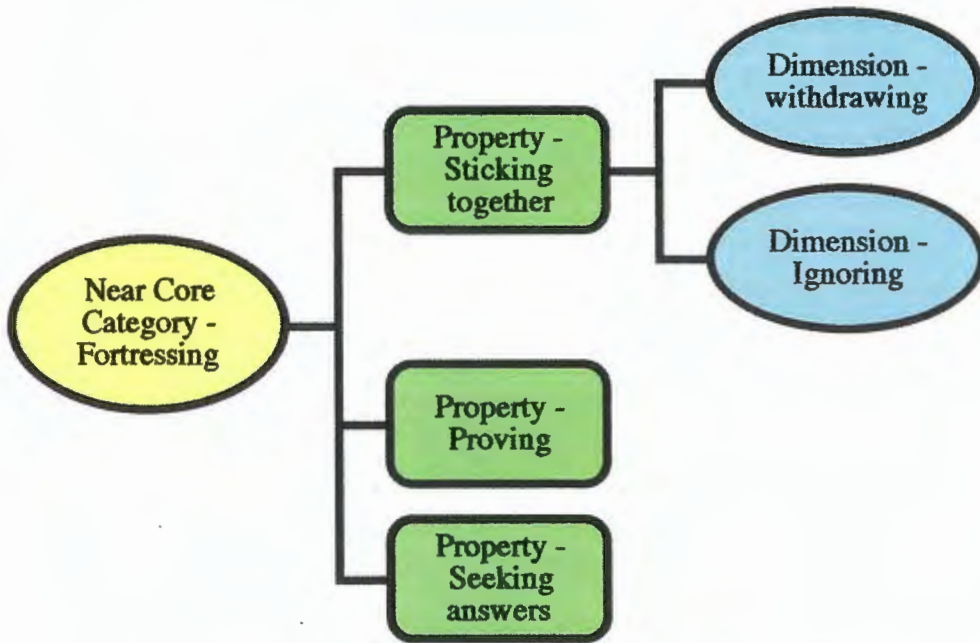


Figure 9. A diagrammatic presentation of the near core category *fortressing* with its properties and dimensions.

Fortressing, as its name implies is a symbol of the protective shield that surrounds an individual. The *fortress* is within the self. It is where each and every one of us retreats when our world threatens our feelings of security. It is the imaginary place where the child afraid of the dark goes to shield them from the imagined horrors of the dark. It is the place where the adult experiencing work place confrontation will retreat, as a self-protective mechanism. For the adolescent with AD/HD whose *scaffolding* (categories in the levels of process) does not protect them from the exigencies of the dark side of their lives, they perceive it is the only safe place to be. The fortress is wherever and whatever, an individual imagines it to be.

Fortressing wove its way inexorably through the basic social-psychological process of Reaching for the Light. The level of *fortressing* (along with *balancing*) at any moment in the life of the adolescents with AD/HD was determined by the needs of the moment and whether they were being supported by the family, school and friends, or Being Treated Differently.

Fortressing, was determined by its properties *sticking together*, *proving* and *seeking answers* and the dimensions *withdrawing* and *ignoring*. The following statement encompassed much of what *fortressing* was all about:

I think we make us, that is people that have been treated differently and wrongly. I think we do like make a mask, like put a mask over or just build a fortress around us so no one can penetrate it and we just hide there and all that. (YJ-2, 549-552)

The property *sticking together* and the dimensions *withdrawing* and *ignoring* were employed in the act of retreating to safety, while the properties *proving* and *seeking answers* were engaged to re-establish a feeling of security and return to the process of Reaching for the Light. For example, the dimension *ignoring* related to how the participants indicated they were distancing themselves from the taunts of others, the ridicule and belittling that was their experience of their social environment, whether at home, in school or with peer groups and friends. *Sticking together* i.e., staying with others like themselves was a way of shielding themselves within a group situation. This property was often implemented in the school situation. The dimension *withdrawing* was linked to *ignoring* but regarded by the adolescents as a separate operation. The differentiation was this: that you can *ignore* someone while remaining within a group, but you *withdraw* to a place of safety. How the concept *withdrawing* evolved came about from statements such as these:

It just depends on who they are. Annoying people [people who upset her] I would probably shut down don't talk go all shy and withdraw. But if it is another group of friends then I will join in (WK-2, 434-436); I think because Mum had lots of problems with Dad and I didn't have to put it all on her and I had learn to cope by myself at school and home and all that. Withdrawing was my way of doing this (YJ-2, 530-540); I said that is not ok I am leaving so got all my shit and went byeeee and got in the car. He lives in Gosnells and I went ok and thought I am going to drive and I opened up the UBD and oops there's a big road Brookton Highway. I got half way to Brookton and then I went ahhhhhhh and turned around just before I ran out of phone (RA-2, 87-93); But when I get really ticked off like my Mum yells at me heaps I have to walk out the back and start punching the shed. (CB-4, 313-321)

By *proving* and *seeking answers* the participants were trying to come to terms with the socially mediated problems they were experiencing and to develop coping strategies to overcome these problems. First, they attempted to find out why they were Being Treated Differently (*seeking answers*), this was particularly noted in the case of the females who experienced significant verbal and physical bullying in school. They *sought answers* from those perpetuating the bullying, but to no avail, for instances:

I do not know why. Why they don't talk to me normally. I have been trying to find out for last couple of years now why but they have not told me yet so heh heh ok. I have practically given up on trying to find out. (YK-3, 280-289)

Second, the adolescents suggested that by developing a greater understanding of him or herself they were better placed to manage the problems they encountered. The participants also indicated that they always felt the need to prove themselves to themselves in order to prove that they could achieve things. To do this they suggested that they were "constantly choosing the carrot of life" (DM-TS1). In other words they felt the need to extend themselves in all areas of their lives to prove their worth.

Where *fortressing* was conceptualised as a protective structure the second near core category *balancing* was about attaining equilibrium in the face of conflict.

The Near Core Category Two: Balancing

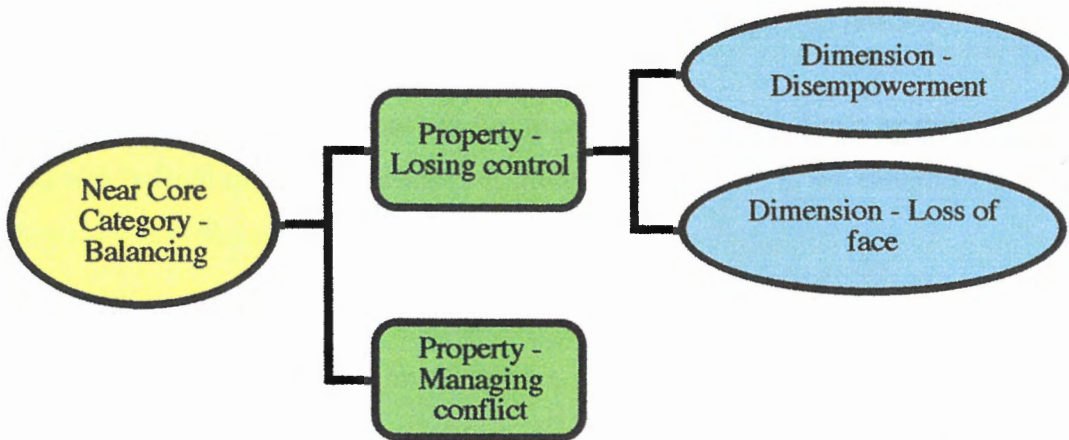


Figure 10. A diagrammatic representation of *balancing* with its properties and dimensions.

This near core category of *balancing* was compounded of interactions and actions aimed at mediating problems that arose as a consequence of Being Treated Differently. *Balancing* occurred at times across all areas of the adolescent's social environment. As with its associated near core category *fortressing*, *balancing* was introduced whenever the need arose within the levels of the core process. As Figure 10 indicates *balancing* consisted of two properties *losing control* and *managing conflict*.

Losing Control.

According to the participants the property *losing control* had two distinct dimensions, these were a *loss of face* and the perception of *disempowerment*.

Loss of face eventuated in two distinct ways either as an internalised perception when the adolescents considered that an action, such as bursting into tears, impinged on others' perceptions of them. The adolescents also considered there was a *loss of face* where *disempowerment* was the result of actions of those around them. *Loss of face* may have resulted from the medication for example:

Now my eyes get all sore. I want to cry about the smallest things. At the start of the year [prior to the medication] I got really angry and I was laying in my room and I wanted to cry and I couldn't and I thought wait a minute and I thought back I hadn't cried for about

three years and I started to cry over that. But now I can get watery eyes over the small things. I just get so worked up and so frustrated that I can't take it and I just have no control over it. (BS-2, 196-210)

Another participant indicated that she *lost face* when she broke down, particularly if this was in front of others, because her life was so difficult. In the statement that follows she is explaining why she attempted suicide:

Well lets' see. I didn't think my life was worth living cause everyone was treating me like crap, sorry can't think of a better word. Oh what else I don't know. Oh being bullied and picked on things like that um outside that nothing much. (YJ-FG2, 196-201)

Participant DM who entered the research during the theoretical sampling phase also discussed depression and AD/HD. She noted that her depression levels deepened and her "problems increased after stopping stimulant medication". Only later, when she came to terms with her negative thoughts regarding stimulant medication and recommenced treatment did her work levels improve and allow her "to work her way out of this depression" (DM-TS1).

Breaking down in public was seen as *losing control* of self; the public face of self was exposed, the fortress was breached. The degree of *loss of face* determined whether an individual's feelings of self-worth were decimated or not. Where feelings of self-worth were reduced *balancing* was required. Participants balanced *loss of face* by minimising or reducing the effect of hurtful social actions such as being bullied or picked on. For example, by making light of bullying and people picking on them participants reduced the hurt of these actions in their own minds. This act of *balancing* hurtful actions was negated, however, when participants located the blame for problems such as being bullied within self and away from the perpetrators of the action, i.e., what did I do wrong? what have I done that makes them treat me like that? (RA; YJ)

In the interview that followed the focus group interview with YJ, quoted earlier, I became aware during our conversation that since our last meeting the problems she was experiencing had led to her becoming extremely depressed and anxious. She also mentioned that she had again attempted to commit suicide. This

participant had for many years experienced extreme levels of verbal abuse and ostracism in school. She had had several changes of school to try and overcome the problems but the problems appeared to follow her. On the last occasion that I met with her we talked at length about the problems she was having. The following composite of answers shows how she described her problems and demonstrates how despite continually *balancing* her life she considered her *fortress* surrounding and protecting self was violated making her life "worth nothing":

When it goes the other way it is like when you say it [AD/HD] and they say cool and suddenly walks off and you never see them again. Then you start hearing rumours about you about you being a psycho and all that stuff. I got a lot of that when I heard accidentally blurted it [the diagnosis] out and the whole school found out in less than two hours. So it was like a whole chain of reaction just going along and rumours started spreading and like (YJ-4, 356-366) I have actually been talking to somebody and think they are my friend and then they have dobbed me off then become my friend and then dobbed me off again. That is what I went through my ... especially with one of my friends who actually blurted out that I had ADD around the school. Well they treat me like I am a nothing like I am low life I am worth nothing. I am worth nothing at all. (YJ-4, 439-450)

The problems stemmed not only from her peer group but also staff in the schools. For example: "At **** [school name] the psychologist she tried to say I was imagining, things like being bullied by the other kids and that it was my fault (YJ-4, 159-161)". While on another occasion, at a new school, this participant was having difficulty with a piece of written work. The teacher informed her that: "It is because you have got a disorder you can't edit properly. So I thought well fine, I try my best if you want it perfect fine" (YJ-4, 530-542). When she asked if the teacher could offer a solution to her problem the response was:

No, she just said just "because you have got a disorder I am going to put you down". 'Cos we get points every day and she said "I am going to put you down 50 because of your disorder of not being able

to edit properly". I am like well how can I do it properly and then I went to my English teacher and said could you help me at lunchtime. When the principal heard she said no you can't do that it is her lunchtime she has got to be with everybody else and I am like well what are you offering to me humf. I nearly went to her and said ok then that is not very supportive of you, ok fine. Then I thought I will have to figure it out by myself by, myself in my own time. I will try to do it with my Mum, or maybe I will try. I haven't been able to have a chance yet because Mum has been busy lately so I haven't had a chance to work on my editing skills because I haven't had the teacher to help me. So its like fine I give up. ... She said "just do it by yourself". Hey look I can't do it by myself you have to help me. She recommended me to write it out 16 times. Like this whole thing until I got it perfect I had to do 16 draft copies before she even accepted it as a good copy. Ok, fine waste of time, oh I did my best - all I can do. (YJ-4, 515-525)

On this last occasion when I met with this participant she had withdrawn totally from all outside social contact, felt very muddled and wanted only to sleep. This participant had tried for many years to balance her life and protect herself from the problems she experienced in her social environment. As the following quotation demonstrates, however, *balancing* and *fortressing*, as actions and reactions to outside influences, have their limitations. It also shows the power of society to belittle an individual to such an extent that they feel the need to totally withdraw. As she stated:

Its ok, bit muddled, bit muddled but that's me. Well there is actually not much to tell because I was so muddled last night. The night before I went out weeding at 10 o'clock. I am just so confused all those things that all happened and attack me at school working around everything. Down and depressed but heh, that's life. Life deals you cards and you have take them. Go away and sleep. (YJ-4, 255-269)

Losing face, while being an internalised notion, was very closely linked with the other dimension in the property *losing control*, that is *disempowerment*. *Disempowerment* emanated from influences outside the self, the experiential factors, as the previous quotations from interviews with YJ demonstrate. In these statements the participant alluded not only to the internalised problems she was experiencing with editing her written work, that caused her to *lose face*, but the feelings of *disempowerment* she experienced. Her perception of *disempowerment* came about when her inability to edit was blamed on her disorder. Her request for help from the teacher was dismissed because of her disorder and no useful strategies for coping with her problem were proffered. In fact, in YJ's view she was even further *disempowered* by the teacher when the teacher instigated what seemed to YJ to be a pointless task, in that she was made to write out the piece in question a further 16 times until the piece was deemed to be correct. In other words, the teacher located the deficit (the inability to edit) within the adolescent rather than acknowledging any fault within the system. It is my contention that the symptoms that relate to AD/HD have no particular bearing on whether an individual can edit a document or portion of text. Editing is a learned technique. One may suppose that in this instance it was the role of the teacher to impart this knowledge. Moreover, as Rief (1993) suggested where an individual has a disorder such as AD/HD extra care was needed to ensure that the knowledge being imparted by an instructor was easily assimilated.

The association between self-esteem and academic success in the school years was noted by Dalton and Dunnet (1992), Robin (1998) and Zubrick (1997). It was their view that self-image (self-esteem) in the school years is directly related to academic self-confidence and by extension academic achievement. It was Rief's (1993) opinion that adolescents with AD/HD required patient, positive and understanding support. These supporting structures were very important if the adolescents were to achieve better levels of self-esteem and improve their academic outcomes. The link between disempowerment and self-esteem in the school sector is depicted in the following composite of answers from three participants. In essence, the feelings presented here were those of the participants whose school experience was less than positive:

When they [teachers] know someone has ADD they don't try with them (BS; PB). They don't bother at all; it doesn't matter what you do (MB2). The smart kids get away with things, you get blamed (CB). They [teachers] do it for no reason; you get upset and angry (PB). It is kind of scary that they try to put you down. Feel it is your fault. Just makes you annoyed (RB). I just go quiet. (WK)

This perception of *disempowerment* did not always stem from the school setting. The participants indicated that peer groups, friends and family also demonstrated a tendency to *disempower* them. For example, the participant WK considered she was made powerless by her mother's decision to no longer include her in a choice of tutor for her, particularly when the mother sighted her disorder as the reason why she (WK) could no longer make decisions for herself. The participant was very resentful when this happened and family conflict ensued. Another participant (BS) displayed feelings of helplessness in the face of the behaviour of friends towards him because he was taking stimulant medication. In his opinion, they seemed to resent the fact that the stimulant medication now allowed him to concentrate on his work and led to greatly improved marks for exams and assignments. His friends accused him of being a 'druggie' and excluded him from decision-making involving the group. The following extract followed a long explanation of how this could occur. It demonstrated forcefully how *disempowerment* may occur outside the school. In the situation in question the group of three friends had gone for a Saturday afternoon drive to the beach, BS (the research participant) had to return for work that evening. His work was very important to him as he was saving to travel to England. His friends were aware of this, he was very much angered, therefore, when they refused to return home until it suited them. He felt very *disempowered* when they would not accede to his request and ignored him. He was even unhappier when he later discovered that another member of the party also had to return for work at the same time as himself yet his friends had failed to mention this:

That is what angered me the most; they didn't really take it on board that I wanted to go back. If they were in the same situation as me they themselves, if there were two against one, say me and A, we would listen to them. If it was K and A they don't listen to me. But

if it was A and me or K and me we would listen to the other person. But I don't think they listen to me as much [since the diagnosis] and that is what angered me. (BS-3, 235-237)

The data indicated that the degree of *disempowerment* experienced by the adolescent participants was influential in determining that individual's perception of self-worth. When an individual perceived that their social environment thought them incapable of decision-making and *disempowered* them, then in their eyes this signified that they were worthless. Those adolescents in the study who experienced greater levels of *disempowerment* appeared more distressed than the others. I also noted during the data collection and analysis process that those who experienced the greatest degree of *disempowerment* and whose supporting structures were poor tended to be more depressed than the other participants. The interconnection between the category *scaffolding* (supporting frameworks) and self-esteem and depression will be discussed later in this chapter. Self-esteem and depression will be discussed further in chapter seven in the context of the Typologies of Support available to the adolescents in my study.

Managing Conflict.

As the diagrammatic representation of the near core category *balancing* (Figure 10) indicated, there are two closely interwoven properties in this category they are *losing control* and *managing conflict*. The previous discussion on *losing control* indicated that adolescents with AD/HD must not only manage their feeling of *losing control*, related to the processes of *losing face* or *disempowerment*, but they also had to *manage the conflict* that resulted from this perceived *loss of control*. In other words, they must manage self and their environment as social interaction and action. *Managing conflict*, as the other property of *balancing*, can be initiated at any moment in the basic social-psychological process of Reaching for the Light. The participants indicated that they *managed conflicting* situations in various ways. For example:

Like when I be goodest also get like more responsibility (that's the word) when I be more responsible, like looking after my brother and all that you get, they get pleased with you and you start to do it

for a long time like more often then you get to stay up more often as well. (RB-3, 340-349)

Another way of *managing conflict* was by withdrawing to a place of safety, as this composite of answers indicates:

I take my work to the scout hut at the end of the road, get out of the house (BS); I just walk out of the class go and sit outside the office wait till the bell and then go to my next class (CB).

The participants also indicated that they sought to understand why conflict occurred and to find ways of trying to resolve any conflict. The following are examples of this:

I was talking to my mate about this. You see at work I have had two jobs. They have been small businesses and both the bosses have continually hassled me quite a lot. I was actually wondering if it was I or whether it was the bosses. Then basically I realised it was from the way my parents treat me. They [his mates] tell me they [his parents] seem to put me down more than build me up. For just general things they are putting me down not building me up so I have just stopped listening. If they are just talking to me and they sound angry I have just stopped listening. I had realised that is what I was doing at both these work places that is why the bosses were having a go at me because I was just not listening to them. This was the result of the home, like just the way I was being treated at home. (BS-2, 101-121)

I realised that my depression had increased with the increase of problems I experienced at school and home after I stopped taking stimulant medication. As I gained in maturity I came to accept that stimulant medication was a necessity for the rest of my life. Also to be more open, to no longer feel the need to be ashamed. (DM-TS1)

Instead of getting angry or something I just like avoid it [conflict] or something like I just pretend it is not that important I can just see that now. (PB-3, 356)

Managing conflict, as my research demonstrates, was also about managing the hostility of others. It is my view that to achieve this the adolescent participants exhibited a level of maturity far beyond their years. They continually resorted to the process of *understanding others* (a property of *transforming* to be discussed later in chapter six) in relation to themselves and then to *transforming* themselves to meet the needs of their world. They accepted that their world was unlikely to change for them that they must "reconstruct themselves to meet societies expectations" (BS; RB; PB-FG1, 1237). My view is supported by Prosser (2002, p. 6) in his study of AD/HD in secondary schools. He contended that:

The big losers are the young people with ADHD. Caught between condemnation from sociological sceptics, and the neglect of their social needs in the medical model, they are attempting to forge their own path. These young people, showing an awareness to the sociological side of ADHD rarely shown by those who would speak on their behalf, are recreating the label, reforming identity and resisting inequalities in school, with varying success.

The following figure, Figure 11 depicts the way in which the categories of *fortressing* and *balancing* are interwoven throughout the process of Reaching for the Light whenever and wherever they are needed.

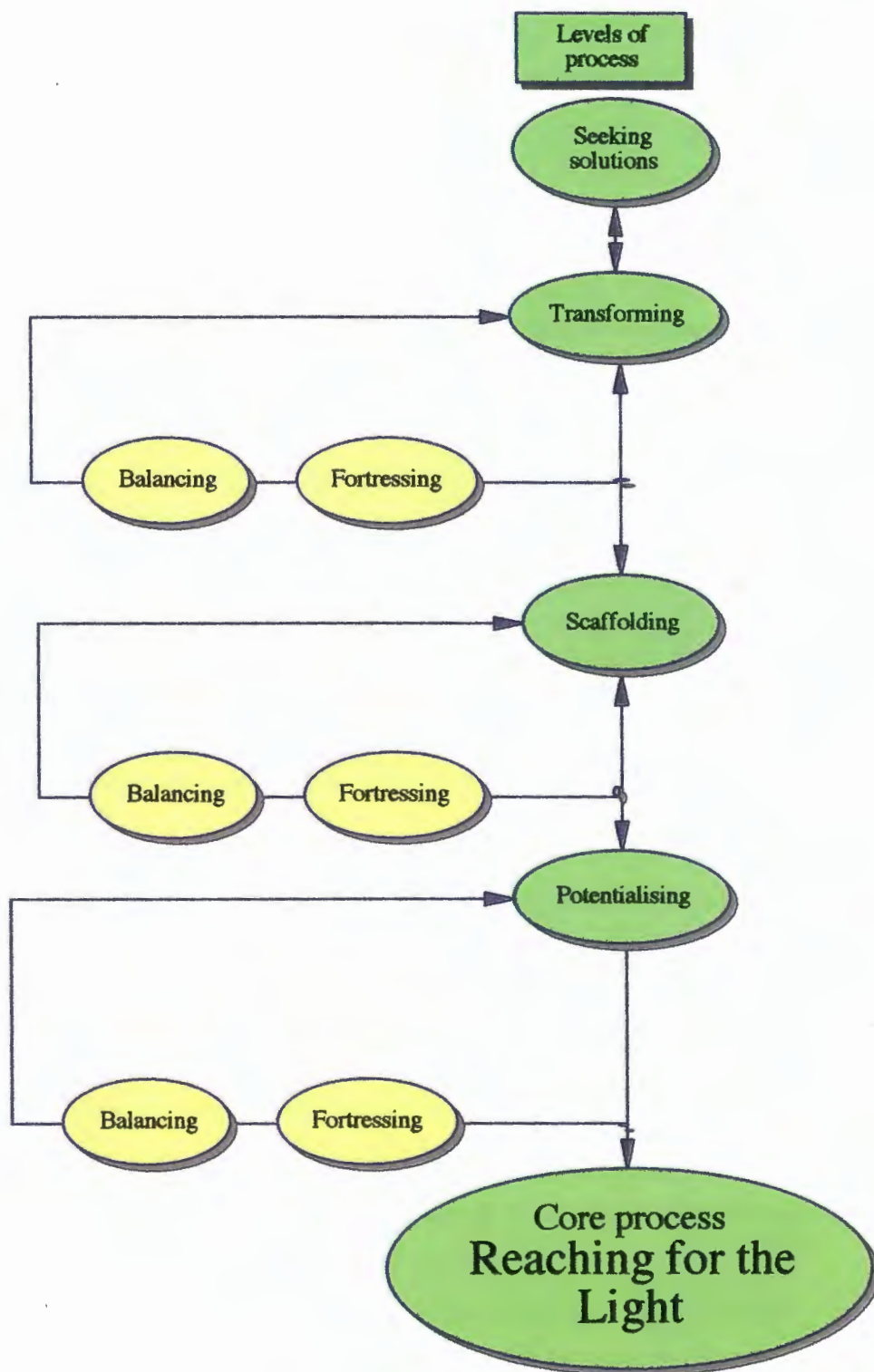


Figure 11. A diagrammatic representation of how *balancing* and *fortressing* are interwoven in the core process Reaching for the light.

In general, social interaction is directed by the process of *balancing*, while *fortressing* is a strategy invoked by an individual to mitigate problems and issues, which that individual finds unacceptable. *Balancing* and *fortressing* are not specific to this group of adolescents with AD/HD. It is my contention that these

processes are symbolic processes that we all employ at times in our lives to manage our social action and interaction. Executive Functions, as discussed in chapter two, permit individuals, through internalised thought to direct individual action and social interaction. Without executive function - discussed by Barkley (1997a; 1997b; 1997c; 2000) in relation to those with AD/HD – individual action and social interaction is compromised. The adolescents in my research, who were all taking stimulant medication, for the most part appeared to demonstrate effective executive functioning. For the adolescent participants *balancing* and *fortressing*, as the quotations presented indicated, were actions they employed to overcome personal or socially mediated problems. The action of *balancing* or *fortressing* would appear to have come about from internalised thought processes. For example YJ instigated the process of *fortressing* as a reaction to the social action of Being Treated Differently. She saw this action as symbolic, as “putting on a mask...so no one can penetrate” (YJ-4, 575). Although in this discussion YJ vocalised her thoughts, her actions arose from a process of internalised symbolic thought in that she saw *fortressing* as a way of protecting herself from the outside world.

Having defined the near core categories and their place in the core process Reaching for the Light, I will now present the four interrelated social processes that have been discovered to be the processes this group of adolescents with AD/HD go through in order to manage their lives.

These four levels of process (referred to as categories) are presented in the following order, *seeking solutions*, *transforming*, *scaffolding* and *potentialising*. The discussion relating to each of these categories their properties and dimensions, which were the stages of process of a category will as before, commence with a diagram to depict the category, its properties and dimensions. The theoretical constructs (such as socialisation) that contributed to this knowledge are also alluded to where appropriate.

The First Category in the Core Process: Seeking Solutions.

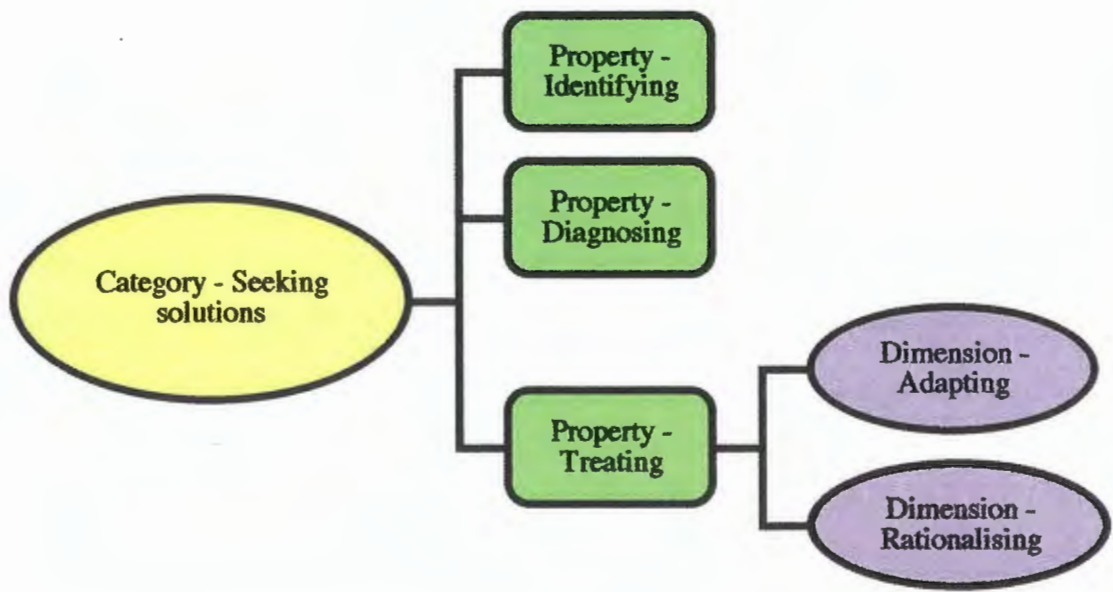


Figure 12. A diagrammatic representation of the category *seeking solutions* and its properties and dimensions.

All the participants indicated that they considered they had a need to *seek solutions* to overcome the problems and issues they and their parents were experiencing. *Seeking solutions* emerged as strategies or tactics designed to overcome or intercede in the problems and issues that had arisen. Six of the participants and their parents did not *seek solutions* to their problems until the participants had reached adolescence. Those parents who sought to overcome these problems prior to adolescence did so with the knowledge of the children because the magnitude of the problems being experienced was so great. As one participant stated, “when the school sends the psychiatrist to your house to talk to you and your parents, you know they think something is really wrong” (RA- 1). This participant, like others who were referred in early childhood to a specialist, had already been asking her parents why she was so different to others, why she was more active than her friends and why they could read while she struggled to do so.

The category of *seeking solutions*, therefore, referred to the process undertaken by parents and children or adolescents in order to overcome a range of intrinsic (epistemological) and extrinsic (experiential) problems. The epistemological problems such as aggression, hyperactivity, poor concentration,

inability to focus on tasks such as reading and daydreaming were of great concern to the parents and adolescents alike, as they led to poor academic achievement. In the main, however, the experiential issues were of greater concern to both adolescents and parents. Experiential issues refer to society's (teachers, relatives and others in their social environment) attitude towards the epistemological problems (seen by society as behaviors) exhibited by the adolescents. It had become apparent to the adolescents and their parents that society deemed these epistemological problems to be inappropriate non-normative behaviours.

Before I detail the properties that form the process of the category *seeking solutions*, I will provide a brief overview of socialisation, medicalisation, labelling and deviance theories as they relate to my research and data analysis.

Chapter two discussed these social theories and pointed out that despite being theories of long standing these theories still direct current social mores, values, expectations and conventions. For example, socialisation and the role of the family in the socialisation process still determine current thinking (Denzin & Lincoln, 2000). Socialisation is the acculturation of a specific group or body of people so that they conform to the mores, values, expectations and conventions of the dominant social group. Socialisation assumes that the fixed roles, values and expectations of a socialising group determine conventions of behaviour. Grbich (1996) suggested that in western society the family is sanctioned to share its socialisation functions with other bureaucratic institutions such as schools and the medical profession. According to Cheek, Shoebridge, Willis and Zadoroznyj (1996) these bodies:

Provide the social monitors whose role is to patrol the boundaries around each differently patterned subsystem. These agents of social control – for example, teachers, nurses, doctors...among others – help to maintain the degree of conformity that can be reasonably expected of people with their roles and norms, and the amount of nonconformity or deviance that can be tolerated. Thus they help society as a whole to maintain its equilibrium. (p. 34)

Taylor (1999) elaborated upon this view by suggesting that when the family combined with the medical profession to socialise children (adolescents) the medicalisation of problems, such as non-normative behaviours may occur. According to Tuchman (1996), society decides how issues that are medicalised, such as non-normative behaviours, are to be accommodated or perceived and how the individual, whose problem it is, is to be treated by society. This then becomes the social information through which status is conveyed to an individual to categorise them. Nonetheless, societal reaction to the medicalisation of problems is open to negotiation, for example, Gerhardt (1989) noted that asthma is deemed to be unfortunate for the individual, but is regarded by society as socially acceptable despite the need to medicate the condition; whereas, stimulant medication treatment for AD/HD is seen as 'drugging children into submission' (McKimmie, 1996; Wender, 1996) and not regarded as socially acceptable. Additionally, society considers the prescribing of stimulant medication to ameliorate non-normative behaviours in children (adolescents) as breaching social conventions and because the behaviours exhibited by those with AD/HD and stimulant medication usage are regarded by society as breaching social conventions they are defined as deviant.

Taylor (1999) contended, that there has been much criticism of the theoretical constructs of illness, medicalisation and socialisation and their impact on society. Nonetheless, as my data analysis will show these sociological viewpoints, along with labelling and deviance theories, are still the experience of the adolescents with AD/HD who participated in my research. The adolescents continually expressed concern that society regarded them as 'different' from their peers. According to Prosser (2002, p. 74), although "biological or genetic differences are the basis of difference and may play a part in ADHD, it is the impairment associated with social norms that redefines these differences". Hutchins (2002) endorsed this viewpoint in his speech at a Sydney conference, when he suggested that those with AD/HD have a disorder, society disables them. Blotzer and Ruth (1995) illustrated this point succinctly when they stated that:

People with disabilities must confront not only their own self-limiting patterns, as traditional views counsels, but the extent to which persons without disabilities treat people with disabilities as unwilling containers of their own fears, limitations and

prejudices.... Their reactions are then expressed in behaviors that must be confronted. (p.6)

Seeking solutions was, therefore, the adolescents and their parents' way of coming to terms with society's reaction to their intrinsic and extrinsic problems. In the opinion of the participants if they could control their intrinsic (epistemological) problems, they could resolve the extrinsic issues (behaviours seen as inappropriate) and their experiential problems, such as being singled out, ridiculed or always in trouble would not occur. The participants were all, however, very concerned about people finding out that they had anything wrong, or that they had been diagnosed with AD/HD. They all believed that this might lead to further problems such as being labelled. The participants were aware that the labelling process tended to marginalise individuals. The participants' perception accorded with the perceptions of Goffman (1974) and Pilgrim and Rogers (1993). Goffman and Pilgrim and Rogers' view was that the more visible the symptoms, the greater the chance of labelling. Once labelled an individual's identity and social status was significantly altered. Where that label was assigned by society to actions regarded as deviant, the individual was stigmatised (Goffman, 1968, 1974, 1990; Grbich, 1996). Maintaining secrecy about their diagnosis was, therefore, an imperative for the participants who were diagnosed with AD/HD.

The category *seeking solutions* has three properties, *identifying*, *diagnosing* and *treating*.

Identifying.

First, within the process of *seeking solutions* is *identifying*. *Identifying* refers to the way in which the parents and the participants discovered or came to understand received information. For example, school reports distinguishing aberrant patterns of behaviour and(or) lack of academic success are taken note of; such as: "I think one of my teachers actually contacted Mum and said "look your daughter is not doing too good at school I am afraid she is not really concentrating very well". So Mum had to contact the doctor, then like ok. So I just got dragged along" (YK: 2 – 21-24). Other participants indicated that they were in serious trouble at school and being suspended for their aggressive or uninhibited actions such as fighting, letting off smoke bombs, not sitting still in class and interrupting

the work of others. For example: "getting into a lot, a lot of fights and swear at all the teachers and never used to listen to what anyone had to say. Just used to run off and do my own thing" (CB-1, 245).

In the process of *identifying* parents also turned to friends and family for advice or corroboration of these facts. For example: "Mum has just been talking to people like my aunty (WK-1, 343)". Parents then viewed received information from friends and family in the context of the home patterns of behaviour of their child or adolescent. The parent then compared these home patterns of behaviour to those reported by the school. The parents also tended to review the scholastic achievement of their child or adolescent with that of other members of the family particularly those of similar age.

Third, the adolescent noted feedback from peer groups and friends relating to expectations of behaviour. They looked at their behaviour in the context of that of their friends. They reviewed their academic achievements and whether they were going to be able to achieve their aims and goals. Their inability to direct their lives and their perception that they needed to address their problems if they were to achieve their aims and goals (to pass TEE, become a nurse, get a job, earn money, have a home of their own) were what directed the adolescents to *seeking solutions*. It was not unusual amongst the participants for them to request that their parents sought a referral to the specialist. As one participant stated, "I asked Mum if I could get some help, 'cos I couldn't control myself. I just couldn't stop myself from doing it [getting into trouble]" (CB-1, 139). All the participants indicated that they were aware they were different to others and that the problems they were experiencing were impacting on their ability to achieve their aims and goals; whether it was to achieve a "good TEE score and go to university" or "to become a bicycle mechanic, or a boiler maker/welder". Comments like "because I just don't understand what they [teachers] are saying and what they are doing" were not unusual.

Diagnosing.

Having *identified* the need for *seeking solutions* the second property within the process *diagnosing* is implemented. A visit to a paediatrician is organised and the problems being experienced by the individual and their parents are discussed. Diagnosis is made after reference to parent and teacher reports. These reports may

be presented in the form of rating scales for example, the Conners Rating scale (Conners, 1969) or SNAP IV (Swanson, 1992). The reports are then compared to a symptom checklist for AD/HD found in the Diagnostic and Statistical Manual for Mental Disorders (American Psychiatric Association, 2000) (see chapter two).

This process of *diagnosing* was seen as one of legitimization. The visit to the doctor was seen as a way of talking things through to get help. As one participant stated "GPs [and specialists] are pretty renowned for being honest they wouldn't sell or make anything else of it illegal or anything like that" (BS-2 545). As another said:

It is ok I just told him about the way people talk to me. Like when people are talking to me I just don't take any notice, I don't take it in I don't I hear it. (Though I didn't say it in those words). When people are talking I know they are talking but I don't take any notice. He said we could give it a trial... [the medication]... and see if it helps. (PB-1, 522-538).

Another expressed the view that "Mum thought and I knew, there was something wrong. It was more than a relief to be diagnosed ADD and to have something kind of wrong with me instead of what is it?" (WK-1, 190-201).

The intervention of the physician to fix things is symptomatic of the medical model of health in that the medical profession is accorded the role 'curing' those seen to threaten society's equilibrium (Davis et al., 2001; Petersen & Waddell, 1998; Tuchman, 1996; Wadell & Petersen, 1994; Wallace & Wolf, 1991, and others). According to sickness and mental illness theories good health is mandatory and sickness is regarded as a deviance or non-conformity to be addressed (Cheek et al., 1996; Davis et al., 2001; Gerhardt, 1989; Petersen & Waddell, 1998). Society's perceptions relating to sickness and mental illness are maintained through societal biases (Barsky & Borus, 1995; Pfuhl & Henry, 1993; Rutter et al., 1998; Whitehead, 1992).

The adolescents were very insistent about their diagnosis, particularly if their diagnosis indicated AD/HD-PI this they referred to as ADD. To them ADD, signified that they were not hyperactive. "I was diagnosed with a minor form. I see a lot of people with ADD and I don't see the difference between them and normal

people but I only see them for a small portion of the day" (BS-1, 568-572). Those who were hyperactive (those diagnosed AD/HD-CT) were regarded as different, "they are the ones you see on the 'tele', going mad and stuff". This need to differentiate ADD and AD/HD was also noted by Cooper and Shea (1998) and Prosser (2000). AD/HD in general is a term that seems to be considered to be more stigmatising than ADD.

Following on from a diagnosis, all the participants were offered stimulant medication as a form of treatment. According to my participants, they were not offered behavioural therapy although they were all provided with literature relating to AD/HD and stimulant medication. The participants did indicate, however, that coping strategies, such as setting time limits on work and establishing consistent rules regarding patterns of behaviours were suggested to them and their parents by the specialist. The specialist also furnished the adolescents and their parents with literature relating to AD/HD and stimulant medication. According to the adolescents the aim of this literature was to assist them to understand their disorder and the use of stimulant medication. Several of the participants admitted that they had not read the leaflets, however, they later asked me for advice or information as they sought to clarify issues. A new book by Ben Polis (2001) and another slightly earlier book by Amen, Johnson and Amen (1996), describing the experience of being ADD were very successful with four of the adolescent participants as these books confirmed to them that they were not alone in their experiences. Two of the adolescents borrowed the Polis book and gave it to their parents to read as a way of trying to demonstrate to their parents how they felt. Although the specialist had counselled the adolescents with regard to any side effects they may encounter from their medication, they were still concerned about the social perception of the disorder AD/HD and the use of stimulant medication. They did not want to be perceived as druggies.

In line with the MTA study (National Institute of Mental Health Collaborative Multimodal Treatment Study of Children with ADHD, the MTA Cooperative Group, 1999) the participants indicated that they considered stimulant medication to be an effective treatment to overcoming their inability to concentrate and organise. The MTA study found that stimulant medication treatment was an effective treatment for those with AD/HD and that stimulant medication treatment

in adolescence was as effective as in childhood. Earlier work reported by Barkley (1998) Robin (1998) drew the same conclusions.

According to the participants they and their parents were concerned about their stimulant medication usage. Their concern stemmed from a fear of social attitudes. The participants suggested, however, that the need to address the epistemological problems they were experiencing prevailed over their immediate concerns. In spite of their concerns, therefore, all of the participants chose, to accept a trial of stimulant medication. In two instances the parents remained uncomfortable with this form of treatment but the adolescents overrode their decision. In one case the adolescent returned, of his own volition, to the specialist and requested stimulant medication without notifying his parents. The reason he gave for this action was:

It was around TEE all the symptoms were there, lack of concentration and I just had trouble studying for long periods of time and during tests and things. Exams that last for three hours after the first hour I would feel I would start thinking about other things and wasting time and was distracted real easy. (BS - 1)

It was BS's opinion that his parents were not considering his current needs and that their decision to deny him stimulant medication to overcome his lack of focus and concentration would impact not only on his TEE score, but his ability to achieve his aims and goals. The specialist considered it appropriate for him to trial stimulant medication to assist him with his problems and as he was over 16 years of age, the specialist issued the adolescent with a prescription.

Treating.

With the diagnosis and the decision to trial stimulant medication the process of *seeking solutions* now moves into the third property that of *treating*. This property has two dimensions *adapting* and *rationalising*. *Adapting*, conceptualised the action continuum undertaken by those who received medication for a diagnosed condition. In my research, the participants found that stimulant medication had advantages. For instance: "yes it helps me focus, concentrate, yeh I never think about them (the problems) they are there, it makes me think, I don't say stupid things when I take the medication. (PB-2, 297 - 308)". The adolescents

also reported that stimulant medication had its disadvantages. They noted that they became more aggressive, cried over small things, (this was of particular concern to the males), "becoming a bit sombre, a bit down bit depressed then getting bit bad tempered (BS-1)". They also found the tablets difficult to take; they were not very palatable and made them feel sick. Both males and females also lost significant amounts of weight. The participants indicated that they were all prepared for these problems, however, following their discussion with their specialist. If the side effects became a serious concern each participant knew that they were at liberty to contact their specialist for advice. There was a tendency, as I got to know each of them better, for them to ring me and ask my advice as well. In these instances I either telephoned their own specialist on their behalf or advised them and their parents to return to the specialist for assistance. The adolescents indicated that in the early days changes were often made to the medication and the specialists gave their parents (and in two instances the adolescents themselves) permission to trial the dose levels to achieve the optimum minimum dose that maximised the advantages and minimised the disadvantages. These findings are in line with research that indicates that careful titration of medication is important (Cantwell & Swanson, 1992; Greenhill et al., 1999; Hazell et al., 1999; Hazell et al., 1996; Rapport, 1992).

Some participants indicated that they believed that their parents and the specialist should have given greater credence to their views regarding the medication, although the majority of the participants considered that they were listened to by their specialist and that they could talk with them whenever they wanted. Two participants, who were experiencing considerable problems with the medication and were unable to develop a rapport with their current specialist, changed to a new specialist with whom each was able to develop a better relationship.

Poor tolerance levels to certain stimulant medication have been acknowledged in the research. Research has also indicated that there is a need for specialists to listen to those taking the medication, particularly when they are mature enough to express their own concerns and to make changes where necessary (Barkley, 1998; Doherty et al., 2000; Greenhill et al., 1999; Hazell et al., 1999; Robin, 1998; B. H. Smith, Pelham, et al., 2000; Tracey & Gleeson, 1998). As Tracey and Gleeson (1998) pointed out, the involvement of adolescents with

AD/HD in their own treatment regimes was imperative if these treatment regimes were to meet their needs and address their problems.

As the participants moved through the stage of *adapting* they began *rationalising* (another dimension of *treating*) their need to take the stimulant medication. This *rationalising* process continued throughout the overarching process of Reaching for the Light. The *rationalisation* process adopted by the adolescent participants was necessary in light of the negative feedback that they were experiencing from their friends and in some instances family members and their own concerns with regard to stimulant medication usage. The following extract demonstrates their thinking:

When people know you are on medication they say what are you taking the medication for? It is exactly the same thing but they go oh he's got ADD. It's labels. But ADD is just like having a headache and you take a Panadol or something like that and it gets rid of it, it doesn't get rid of it straight away, but it gets rid of it. No one labels you as headache man or something like that. (RB-2, 132-137)

The process of *rationalising* also included statements such as:

It is only the last six months that I have taken them. After a while you get used to them. I got used to them pretty much and thought oh I will get used to the sensation and control it whatever and I can be more friendly or whatever while taking them but I think it will take time. Yeh to control it. (BS-1).

The adolescents with AD/HD now progressed from the first category of the process *seeking solutions*, when they began to be able to take control of their lives, to the second level of process, which was *transforming*. While the process of Reaching for the Light was both sequential and cyclical, following identification, diagnosis and the commencement of stimulant medication usage the adolescents needed to return to seek solutions only when their medication required adjustment or it became apparent that their diagnosis may require revisiting as comorbid conditions, not previously identified such as depression and reading difficulties,

became apparent. For the most part *seeking solutions* served only as a platform from which they could launch themselves into a process that allowed them to try and meet their aims and goals and manage their lives.

From *seeking solutions* the participants progressed to the next category *transforming* as they sought to achieve their aims and goals and Reach for the Light.

The Second Category in the Core Process: Transforming

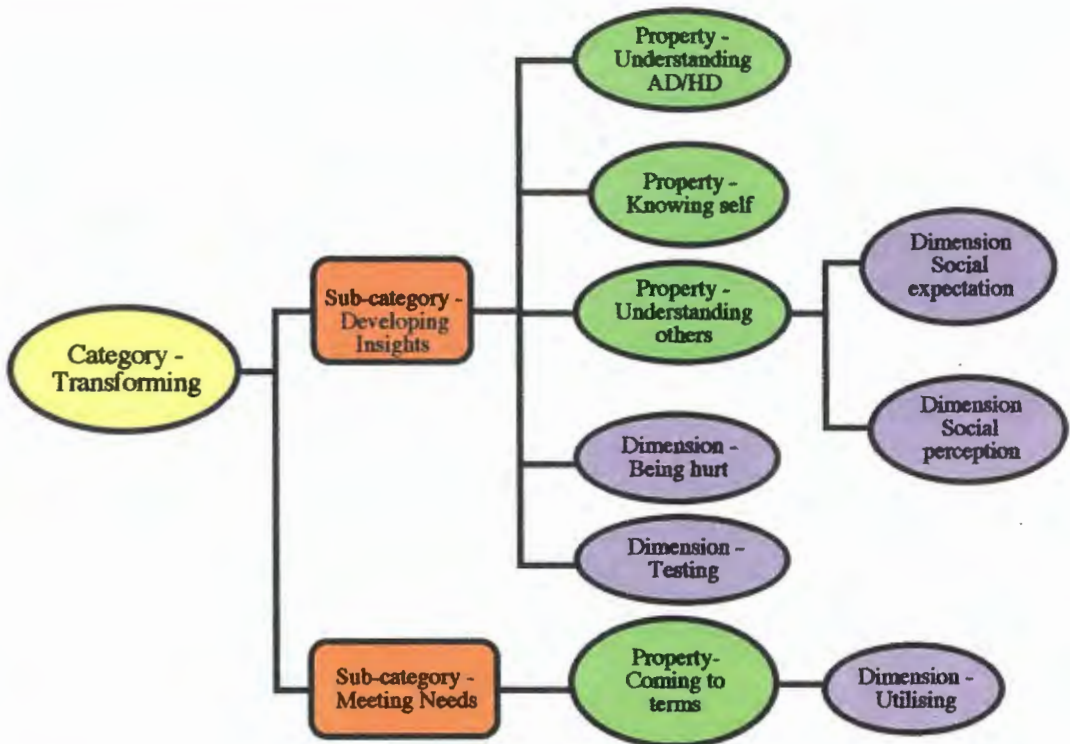


Figure 13. A diagrammatic presentation of the category *transforming* with its sub-categories and their properties and dimensions.

Transforming was where the adolescents diagnosed with AD/HD came to terms with managing the problems and issues related to their disorder while making judgements about their social experience as they related to their diagnosis and treatment. *Transforming* referred to the way in which the participants sought to reshape their identify, their self. *Transforming* was a significant step forward for the adolescents as it signified that they are beginning to take charge of their lives and to rationalise the need to make changes in their actions and interactions in their world in order to achieve their aims and goals.

This process of *transforming* was consequential in that the adolescent participants with AD/HD were not only acknowledging their problems (which until then many of them suggested they had tried not to do), but they are also beginning to notice other difficulties. Prior to their diagnosis and medication trial, although they were aware they were different to their peers they suggested there was a tendency for them not to accept society's (i.e., teachers, parents and peer groups) attitude towards them, which in their experience was often negative. It was only when these problems (such as getting into trouble and being ostracised) severely impacted on them that some, but not all of them, sought or requested their parents to seek medical assistance. In some instances the participants indicated that it was when they came to a critical point in their lives that they finally concluded that they needed to take action. For example:

I used to get into a lot a lot of fights and swear at all the teachers and never used to listen to what anyone had to say just used to run off and do my own thing. I just got frustrated punch walls, head butt walls. If someone was in the way I would go up and hit em. Used to get in trouble a lot. (CB-1, 53-65)

In this instance CB went on to explain that on the last occasion he broke his knuckles in his right hand. At this point in time he asked his Mother to take him to the doctors to "get the doctor to do something" (CB-1).

According to the participants, medication enabled them to focus and concentrate and become more aware of themselves and their actions and to be aware of society's attitude towards these actions. They expressed the view that this knowledge allowed them to realise that there was a need for them to *transform* themselves.

The category *transforming* will be discussed in greater detail shortly. First, however, I wish to briefly reflect on adolescent development in the context of the discourses that dominate identity and the construction of adolescent identity in western society. I discovered during data analysis that these discourses along with socialisation, medicalisation, labelling and deviance appeared to influence the thinking of the research participants.

The complex issues relating to the developmental model of adolescence in western society have been the treatise of many theorists including Piaget, Erickson, Vygotsky and Foucault (D. Moore, 2002). Piaget's core notion was that as adolescents undertake adult roles they begin to plan ahead and think more systematically about their world. Erikson portrayed adolescence in terms of a complex struggle to create a coherent individual identity out of identity confusion and potential diffusion (D. Moore, 2002). Foucault's discourse centred on three processes of social control and power. Through these three processes, 'dividing practices', 'scientific knowledge', and 'technologies of self' human beings are made subjects (D. Moore, 2002).

Foucault's thinking with regard to self and society as defined by his 'technologies of self' is mirrored by Blumer's (1969; 1976) symbolic interactionist perspectives that underpin this study (as discussed in chapter three) and Goffman's ((1971; 1974; 1990) seminal works on the presentation of self in everyday life, particularly those relating to labelling and stigma. The philosophies of these scholars stem from the notions of Vygotsky who, according to Ratner (1991, p. vii), asserted that "psychological functions are quintessentially social in nature... they are constructed by individuals in the process of social interaction...and embody the specific character of historically bound social relations".

Taken together these discourses endorse ways of writing, thinking and speaking about certain objects such as adolescents, as subjects thus setting up subject positions such as 'deviant' or 'mad' that sanction marginalisation.

As the discourses on socialisation and adolescent development dominate the way in which the adolescent world is constructed it was not surprising that these discourses dominated my participants' view of their social experience and allowed them to form the perception that they needed to *transform* self (to reconstruct themselves) so as to conform to social conventions. The strategies employed by the participants, were thus designed to deal with the specific systems of power (e.g., the classroom, the peer group, the family) to prevent marginalisation and stigmatisation and allow the adolescent participants to achieve their aims and goals to Reach for the Light.

It is not my intention to question or argue about the adolescent developmental paradigm or socialisation, medicalisation, labelling and deviance theories that currently inform western society's thinking but merely to present them in order to try to explain how the adolescents came to their way of thinking. In other words, I have endeavoured to overcome the different cultural worldviews that stem from my being an adult while the participants are adolescents and present the adolescents' perception of their world, not my adult perception of their world.

Managing their lives depended on the adolescents accepting social conventions as they are determined by socialisation and the adolescent developmental paradigm. The process of *transforming* was thus the participants' way of addressing these social discourses so they may manage their lives.

The process of transforming had, as Figure 13 indicated, two sub-categories, these were *developing insights* and *meeting needs*. *Developing insights* was viewed in the context of its properties, which were: *understanding other*, *knowing self*, *understanding AD/HD*, and its dimensions *being hurt*, and *testing*. In the property *understanding other* two further dimensions became apparent they were *social expectation* and *social perceptions*. *Meeting needs* was constructed of a property *coming to terms* and a dimension *utilising*.

Discovering Insights.

The first sub-category of *transforming* that I will document is that of *developing insights*. This is a consequential and complicated sub-category. Where for adolescents with problems symptomatic of AD/HD *seeking solutions* started the process of managing their lives this sub-category, *developing insights*, and its properties and dimensions further clarified and specified the category of *transforming*. By *developing insights* the adolescents were sanctioned to consider how they are going to approach their lives in the future in the context of the dominant developmental paradigm and socialisation that informed their worldview and that of their social environment. *Developing insights* was, therefore, critical for the adolescents with AD/HD who participated in my research if they were to achieve their aims and goals.

The property *understanding AD/HD* tended to occur in conjunction with the properties *knowing self* and *understanding other*, and the dimension *being hurt*. As the adolescents came to *know themselves* and understand about their social experience so they began to construct a picture of what AD/HD is all about. It was not just the physical problems or failures in their mental processes that they experienced with AD/HD such as, concentrating, not doing stupid things, poor eye-hand coordination, or being able to control themselves. Rather, *understanding AD/HD* was about understanding the total experience of the disorder. The adolescent participants considered that their medication assisted them to overcome the personal problems they experience in their lives as it allowed them to process information, to focus, to concentrate and to organise self. The participants realised, however, that their medication, due in part to the media's negative perception about stimulant medication, is regarded by society as a 'drug' in line with cocaine. Moreover, while society remains locked into socialisation and the medical model of health, where the labelling of those whose behaviours (including the usage of stimulant medication) are deemed inappropriate continues, in the participants' opinion those with AD/HD will remain marginalised. "There is a stereotype with people with drugs and ADD people" (BS-2, 18-28). You understand you are considered not normal ... [this is because]... you are not doing the things other people expect of you. (BS-3, 590-593).

It was the adolescent participants' perception that media stereotyping and prejudice significantly influenced the way they were treated. In their view those with AD/HD are portrayed as badly out of control and dangerous, and comments made in the media like 'drugging our children into submission' were extremely unhelpful. All the participants accepted that they were different, but as they pointed out "I don't know why it is bad to be different why does society see being different as a bad thing?" (RA- 1). Another participant gave as an example a television programme that he considered was an inaccurate and a harmful portrayal of those with AD/HD:

Like the stereotype of ADD. The psycho little kid, who doesn't listen to his Mum, breaks all the things. Like I saw the Today Tonight (Australian television show) thing where - I hate that show it is so biased such dodgy reviews. - This little kid he was like ADD

he was breaking things in the house and yelling and screaming and swearing at his parents and he was just out of control and they were like doing a report and saying this is the average ADD. I thought what are they talking about, that's not true. (BS-2, 356-364)

Another participant expressed the view that "the media treats ADD as a fashion accessory and an excuse. This reflects on those with ADD" (DM-TS1).

Without exception the participants in my research were of the mind that there were many instances of inaccurate and misleading media reports, both in the papers and on television, and that these reports influenced the public perception of AD/HD and were detrimental to those with AD/HD. The many scholars and health professionals involved with those with AD/HD support the participants' perceptions relating to the media. As the Consensus document (Barkley, Cook, et al., 2002) indicated, the inaccuracies and misunderstandings associated with the disorder AD/HD, and the harm these do to children and families are enormous. Hazell (2002) too argued that AD/HD:

Continues to receive a disproportionate amount of media attention relative to other psychiatric disorders of childhood. Recurring themes include the concern that the medical profession may be pathologizing normal childhood behaviour, and reservations about the use of drugs that have the potential for abuse as first line treatment. (p. 475)

The media plays a considerable role in determining social perceptions of individuals. According to David Moore (2002), moral panic is defined by Cohen as arising from a condition, episode, person or group who are regarded as threatening to society. Youth has traditionally been the subject of many moral panics around violence, drug use, and unconventional behaviour (D. Moore, 2002). In Furedi's (1997) opinion, moral panic is pervasive and creates a culture of fear based on securing society from the risks associated with some food, or drug, abuse or crime. Michael Moore asserts that moral panic is media driven hysteria in society (M. Moore, 2002). Michael Moore's (2002) documentary film *Bowling for Columbine* demonstrates how the media may construe moral panic in society. This documentary discusses a high school shooting at Columbine (USA) and questions

why these young people carried out the shooting. The documentary challenges the norms in the United States in relation to gun laws and the media's influence on society. Moore contends that the all-pervading influence of the mass media in the United States has developed in the general public an overwhelming sense of fear for certain social areas. For example, whenever a crime is committed in America the media tends to blame the stereotypical young black male. This is despite, as Moore (M. Moore, 2002) pointed out, that the majority of crime is statistically proven to have been perpetrated by white Anglo-Saxon males. Moore quoted the following statistics to support his claim of how the a media driven culture of fear may be perpetrated: in the United States over the last decade gun murders have decreased by 20%, but media reported gun murders have increased by 200%. It is this media driven moral panic which I contend is the experience of those with AD/HD. Headlines such as, ADD drug may change brain (2001); Attention deficit disorder: another ailment in search of legitimacy (2002); Drugging kids behaviour (2002); Premature babies face double AD/HD risk (2002), and 400 pills at school a day: Head (Fang, 1999), are promoting fears that disturb the public need for social order. It is headlines such as these that encourage a divisive view of those with AD/HD and assigns them the role of victim pitted against a group of oppressors. *Understanding AD/HD* in the context of coming to terms with and accommodating others viewpoints as part of the transformation process was thus critical to the adolescents if they were to achieve their aims and goals and manage their lives.

The second and very important property of the sub-category *developing insights* is *knowing self*. As the adolescent participants came to know themselves and establish their own identity they were able to begin to manage their lives and to develop coping mechanisms, that permitted them to Reach for the Light. *Knowing self* was intrinsically linked with the other properties of this sub-category, in particular *understanding others*.

An adolescent can develop insight into who he or she is at any given moment (*knowing self*). Thereafter, it would appear that adolescent depended no longer on what others believe, but rather on who he or she wants to become. With the ability to understand abstract thought comes a profound awareness of who one is (self-concept) (Jaffe, 1998). The notion of abstract thought as Barkley (2000) indicated stems from the Executive Function areas of verbal and non-verbal

working memory self regulation and reconstitution. As an individual comes to understand or to *know self*, so too does socialisation and social intercourse promote self-control because the individual must restrain his or her own desires in the interest of social coordination and convention (Ratner, 1991).

Knowing self in the context of *understanding others* and in the presentation of self, as Goffman (1990, 25) indicated:

[becomes] a performed character,...not an organic thing that has a specific location, whose fundamental fate is to be born, to mature, and to die; it is a dramatic effect rising diffusely from a scene that is presented, and the characteristic issue, the crucial concern, is whether it will be credited or discredited.

Related to the property *knowing self* within the sub-category *developing insights* was the dimension *being hurt*. *Being hurt* was an in vivo code, which was directly related to the problem of being labelled. Although *being hurt* may be construed as an emotive response to the attitude of others in their lives, it was a very relevant dimension for the participants for if or when *being hurt* became overwhelming and turned to self blame then, as the data indicated, there was a tendency for depression to emerge as an outcome of *being hurt*. The degree of *being hurt*, therefore, influenced personal outcomes for the adolescents with AD/HD. Where depression may have been a side effect of the medication in this instance, according to the adolescent participants, depression was an outcome of their social experience of Being Treated Differently (depression and self-esteem will be discussed later in this dissertation).

The third property of the sub-category *developing insights* is *understanding others*. In this property the adolescents were coming to terms with the expectations of socialisation and what this meant to them. This property had two interrelated dimensions, these were *social expectation* and *social perception*. During the first focus group discussion the adolescents came to the conclusion that society expected them to conform to social values, mores, expectations and conventions i.e., to be socialised. To accomplish this the group suggested that "we conform to society. Yeh, we change for society - they force us. We do it ourselves but they force us to do it (Focus Group 1-PB, BS RB, 293-298). Through the dimension

social expectation the adolescents developed an understanding of their relationships with adults and their peers/friends in light of their diagnosis and their use of medication. This understanding produced a singular caution due mainly to the participants' perception that if they were not careful they would be victimised and treated differently (basic social problem). For while the adolescent participants were developing their own understanding of the others in their lives (peers, family, teachers), they also had to contend with the conflicts that were associated with these others in their lives. The desire to conform to *social expectations* was a common thread not only in this study but also those of Cooper and Shea (1998) and Prosser (2000). As Cooper and Shea (p. 46) indicated, "a striking feature of these student interviews is the almost universally shared desire to behave in socially acceptable ways and succeed in school".

Associated with the dimension *social expectation* was another dimension of the property understanding other, this was *social perception*. The adolescents perceived that the disorder AD/HD had a negative image, hence their fear of labelling discussed earlier. As already argued, labelling brings with it constraints particularly where a disorder is medicalised, in that medicalisation brings with it the knowledge that the individual who is diagnosed with a disorder and considered to be breaching social conventions must be 'cured' if they are to be accepted back into society (Gerhardt, 1989; S. Taylor, 1999). Failure to meet these social requirements leads to an individual being considered as a secondary deviant and further marginalised (Cheek et al., 1996; Gerhardt, 1989). The *social perception* of AD/HD in the participants' eyes led to them Being Treated Differently and was a significant problem to adolescents who participated in this study. They reacted very resentfully to the way they were ignored or treated as though they were stupid because they were diagnosed AD/HD, and were fearful of others finding out that they had AD/HD, as they were anxious about public ridicule. They considered they were discriminated against or marginalised and that society sought to disempower them. The participants expressed concern at the way in which they were treated at home, at school and socially. They only wished for "people to treat me the way they would like to be treated (CB-2, 149). It was particularly noted that *social perception* seemed to influence the female experience at school and with their peers and appeared more negative than that of the males. The males were also aware of this and suggested that where "boys would get into a barny, girls could be

very verbal" (PB-FG). It was the participants' view that social conditioning sanctioned males to be more energetic, more hyperactive i.e., boys will be boys. Whereas, females who exhibited this kind of behaviour were not so readily accepted, as they did not conform to the social mores for 'young ladies'. The participants also reiterated the point that within the peer group males tend to be more accepting of non-conformist behaviour, whereas, females will resort to ridicule, name-calling and ostracisation of those who do not meet their rules. A study by Blachman and Hinshaw (2002) corroborates their thoughts. Their study indicated that girls with AD/HD tend to be less well liked by peers in general, were more inclined to have no friends and less likely to have multiple friends. Their friendships tended to be less stable and include more negative features.

The final area of the sub-category *developing insights* to be discussed is the dimension *testing*. All the adolescent participants (included those who participated in the theoretical sampling phase) indicated that they had tested the usefulness of their medication at one time or another. According to the participants they did this to verify whether the medication was necessary for them to be able to manage their lives, and whether the medication enabled them to accommodate the needs of society from the point of view of appropriate social behaviour. They were aware that the adults in their lives viewed this as non-compliance and rebellion (chapter two). As Asmolov (1998, p. 9) contended, however, the psychology of personality and the postulate of compliance sees the real world of the individual reduced to a "world of impersonal social norms", where compliance becomes subordination in order to conform to given norms. Rather than being compliant, however, the participants took the view that part of managing their lives was managing their medication. Their reasoning was that they could not effectively accomplish this without stopping (*testing*) the medication and noting their own actions and the reactions of others around them. Some of the participants indicated that this brought considerable problems, such as being grounded for inappropriate behaviour like throwing a stone at a friend in fun without noting where it was going to end up. The result was a broken front window in the house. Understandably, this action did not please his parents. The participant accepted that his behaviour was inappropriate and his thoughtless action a result of not concentrating. Several other incidents relating to thoughtless and uninhibited behaviour were also made known to me. On reflection each of the adolescent

participants came to accept that the medication provided them with the ability to control their behaviours. Without stimulant medication they considered that they were unable to concentrate and organise themselves. All the participants, therefore, returned to using stimulant medication. Moreover, two of the adolescents went so far as to express the view that they irritated themselves when they were not on their medication. Although one group (two participants) who were AD/HD-PI noted that they could manage their behaviours to a degree without medication but where concentration (such as with home work, exams etc.) was required then the medication was essential to them. Prosser's (2002) study also noted this selective use of medication as a tool to cope with stressful situations, such as exams. This appreciation by the adolescents in my research that they needed the medication to improve the academic outcomes and to facilitate self-control in order to manage their behaviour was surprising, in light of studies by B.H. Smith, Pelham, et al. (2000) and Doherty, Frankenberger and Fuhrer (2000). Smith, Pelham, et al.'s study noted that adolescents with AD/HD were better able to assess their social relationship, but less likely to be aware of their academic needs. The study by Doherty et al. indicated that adolescents take stimulant medication in order to improve social and behavioural effects rather than enhance their academic outcomes.

The adolescent participants indicated that there was a need to go through this process of *testing* for two reasons. First, the side effects of the medication, particularly the feelings of sadness, and a tendency to aggression or intolerance towards others concerned them - a finding supported by Doherty et al.'s (2000) study. Second, the negative social attitude towards the use of stimulant medication from their peers, teachers, and in some instances their families led them to question the wisdom of medication utilisation.

By the conclusion of my research data collection all but one of the participants had returned to medication usage, when they deemed it appropriate in order to be able to manage their lives and achieve their aims and goals. For the most part, however, with the exception of three participants, they preferred that others did not know they were taking the medication. Towards the conclusion of my data collection I became aware that one male, who had experienced very negative feedback from his parents and peers with regard to his medication, had again discontinued and may have substituted his medication with marijuana.

The struggle to cope with social issues associated with AD/HD, as a specific feature of AD/HD in adolescence, was a factor also noted by Prosser (2002). Although, unlike Prosser's experience where many participants in his study did not see the link between their struggles and issues such as depression, drug use, and suicidal thoughts, the adolescent participants in my research were all aware of the social and epistemological implications of AD/HD and the impact on their lives. They were also determined to overcome these issues and achieve their own aims and goals, to Reach for the Light.

Meeting Needs.

Meeting needs is the second sub-category of the category *transforming*. It has a property *coming to terms* and a dimension *utilising*.

With the property *coming to terms*, the adolescents indicated that they had come to better understand their medication and the way in which it assisted them. A composite of their views on medication were that it allowed them to:

"Get better grades" (RB), "I don't get into trouble at school any more" (CB), "become more settled", "set your mind to doing things" (PB), "before it was hard, settles me down gives me control" (BS), "when I am on my tablets I am able to make a conscious effort with myself", it is a "helpful drug. Not like others." (CB) (Here the participant was referring to drugs such as heroine and drugs known as designer drugs, or 'speed').

When I am on my medication I can knock people dead. I can just turn around and say something really good. I can now do deadpan expressions really well. I continue to scare my friends by saying stupid stuff with a really dead straight face. Like the game of sausage in year four. (RA- 1 364-368)

Like the participants in Prosser's (2000) research my participants expressed a view that medication is a means to control either their own actions and improve interactions with teachers, parents and friends.

Under the *in vivo* heading of *coming to terms* the participants discussed the use and abuse of stimulant medication at school and indicated that they were aware that some of their peers with AD/HD sold their medication. The consensus of opinion amongst the participants was that "I need my medication so why would I sell it?" In a review of research into the misuse and abuse of stimulant medications by Rabiner (2003) the following statistics were noted in a study by the Massachusetts Department of Public Health. This study found that one-third of those taking medication to treat AD/HD at a number of Wisconsin (USA) schools had been approached to sell, give, or trade their medication while 10% stated that this was a frequent occurrence.

In our conversations the participants often introduced stimulant medication and drugs as two distinct subjects. I considered that it was very important for me to remain non-judgemental during these discussions if I was to present my research as the voice of the participants. I, therefore, accepted that we had differing cultural perspectives on certain issues, particularly relating to the use of drugs. I accepted with equanimity their views on drugs and drug taking within the community, even when my views did not correspond with theirs. I considered it was not my place as researcher to do more than provide information when it was asked of me. In this way I found that the participants tended to confide in me, while commenting that I was cool and they would never talk to their parents or other adults in the same way. I became aware that they were very knowledgeable about various drugs. Participants such as RA also noted that they were aware that 'drugs' and stimulant medication did not mix and while they did occasionally use drugs they did not take their stimulant medication at the same time. Using drugs such as marijuana is consistent with a study by Molina and Pelham (2003) that noted where the majority, 80%, of adolescents with childhood diagnosed AD/HD did not report drug use, 20% of adolescents with AD/HD who were diagnosed in childhood were more likely to have used alcohol, cigarettes, or marijuana than their peers without AD/HD. A study by Wilens (2003) concluded, however, that stimulant medication use reduces the risk of drug and alcohol use in AD/HD except where Conduct Disorder symptoms are comorbid with AD/HD.

It is my view that the participants singularly demonstrated their ability to *come to terms* (a property of *meeting needs*) with their world by *developing insights* about themselves (*knowing self*) and in the way that they came to

understand what society (that includes the parents, friends and school) expected of them (*understanding others*). As one of the adolescent participants stated:

Actually, recently I have been developing a lot of philosophies just on general things. I have been thinking why am I thinking about this? I wouldn't usually think about this. Things like personality things, like why I do certain things or behavioural patterns. I look at other people and compare it to myself. I wouldn't usually do that. Whether it is theory there. Sometimes I see personality traits in me that other people have and some I have that other people don't. I am trying to relate other people to myself to see how I would react in certain situations. (BS-3, 189-201)

Utilising, as a dimension of *coming to terms* was also associated with stimulant medication use. *Utilising* referred to how the participants *come to terms* with social perceptions and attitudes towards their stimulant medication usage. With this dimension the adolescents discussed once again the advantages and the negatives of their medication that they had become aware of. Unlike *testing*, in which they reviewed the usefulness of stimulant medication to overcome their epistemological problems with *utilising* the participants were explaining why and how they overcame social adversity (their experiential problems) in order to manage their lives. As the adolescents considered they were beginning to take charge of their lives, as in *coming to terms* and *testing* they again reviewed whether or not to take their medication. They did this by weighing up its advantages and disadvantages. For example:

I still know all the things I can do like when I am on my medication
I know there is nothing that I can't do. I can do whatever I want. I
can be whatever I want. I can go wherever I want if I want to. (RA-
1, 134-140)

This participant was very clear about her beliefs about her medication and what it did for her, even in the face of negative remarks from her close friends. Her boyfriend had suggested that she should stop her medication entirely. She was not prepared to do this, saying:

I hate who I am when I am not on my medication. I am two different people. I am Sarah [pseudonym] when I am on my medication and I am Sarah when I am not on my medication. But I don't class them as the same person. They are two completely separate persons and I haven't seen that other person for the last five years of my life. (RA-2, 95-105)

According to her, the boyfriend had implied that she was not herself on the medication. This upset her greatly, as she said:

He basically said that who I am when I am not on medication is who I am and when I am on my medication that is not who I am. I am really this person I hate and I, it really did my head in like it brought my whole reality crashing down. Because I am so proud of the fact that I can say I know who I am and that I like who I am. Then somebody that I really care about basically tells me that is not who I am and that for the last five years of my life I have been pretending to be somebody that I am not. (RA-2, 110-208)

In instances such as this the near core category *balancing* was introduced.

As this discussion has already intimated, for adolescents with AD/HD the way was fraught with many problems. First, there was the basic social problem of Being Treated Differently and its ramifications such as social discrimination, victimisation and labelling encouraged by the histrionics associated with some of the mass media. Then there were the expectations of the socialisation process and the medicalisation of their problems to contend with. The category *transforming* its sub-categories and their properties and dimensions was, therefore, for the adolescent participants a very important process. It was through this process of *transforming* that the adolescents indicated that they were aware of the many problems and issues that confronted them. Through the actions inherent in the process of *transforming* such as *developing insights* and *meetings needs* they sought to begin to overcome their difficulties and to manage their lives.

The third category in the basic social-psychological process of Reaching for the Light is that of *scaffolding*. This category was a significant part of the process as it forms the supporting framework for the other levels of process.

The Third Category in the Core Process: Scaffolding

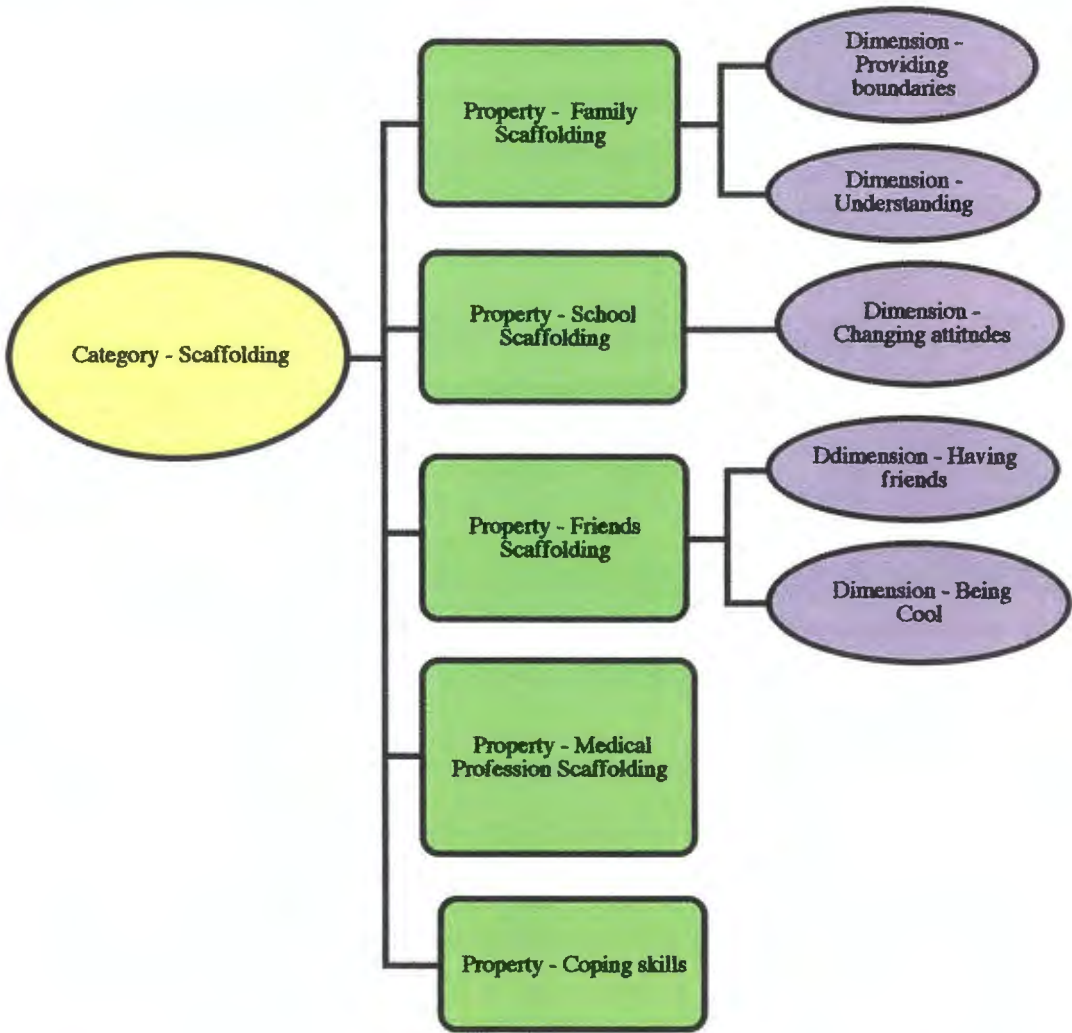


Figure 14. A Diagrammatic presentation of the category *scaffolding* with its properties and dimensions.

The category *scaffolding*, an in vivo code word, had five properties *family scaffolding*, *school scaffolding*, *friends* (this includes peers) *scaffolding*, *medical profession scaffolding* and *coping skills*. These categories conceptualise the process of building supporting relationships and intrinsic coping skills that assisted the adolescents with AD/HD to effectively manage their lives. Their supporting frameworks came from within the family, the school, (including teachers and peer groups) and friends and at a greater distance, the medical profession. In the context of the basic social-psychological process the *scaffolding* metaphor,

therefore, denoted the structure that surrounds the individual to protect them from the exigencies of the outside world and to improve their outcomes. Without adequate *scaffolding* the *fortressing* as a protection against Being Treated Differently can be violated. For example, if an individual was deficient in learned coping skills they will have difficulty in achieving their aims and goals, whether these were to go to university or to become a bicycle mechanic. My research indicated that those adolescents diagnosed with AD/HD without support from their social environment were particularly vulnerable and demonstrated a tendency to become depressed if they considered that their support network was not available to them.

The *coping skills* were the learned strategies employed by the adolescent participants with AD/HD to overcome their epistemological problems. These strategies included programmes related to learning how to know, or a process entitled 'mind matters'.

Positive *scaffolding* (i.e., support) from the social environment was critical to an adolescent with AD/HD as it signified approbation and acceptance of them as an individual. The adolescents envisaged their *scaffolding* frameworks as:

The picture is like this. The picture is cut in half. The one side is rain, pouring rain and the other is sunshine and you can go there and be happy lots of support, whereas, all the black and the rain is the dark side is like no support, bad support and all that. You just feel like you are completely muddled again. But on the happy side it is sun shining and you are happy. You are confident about being yourself and all the good support around you. (YJ-4, 211-219)

When they considered that the support was not there or was very negative, they looked to others for help before retreating to their *fortress*. Other areas where participants sought support included counselling and youth agencies (including the State Child and Development Centre and Youth Focus).

While YJ's previous quotation was very poignant, the following quotation by RA is very graphic. It presents a very clear picture of what being unsupported was like for those who experienced it. The participant in question was very upset at the time and had telephoned me to ask to talk about the problem she was

experiencing. In this instance the support (in relation to her medication) that she had expected of a friend had collapsed around her, leaving her feeling very vulnerable.

Everything like just went shit house²⁰ and all I can think was to ring you and talk to you about it. Because you always seem to agree with me. But even if you didn't agree with me, you have got enough background that I would allow your opinion to be creditable. Do you know what I mean? I hate sitting there and listening to people whose brother's ADD and they know everything about it and they know what it is like and they know how it feels. Because fucking bullshit. You can't explain to somebody how something or someone feels. (RA-2, 268-275)

Family Scaffolding.

The home and family was the most important supporting environment for the adolescents with AD/HD. When their extrinsic (experiential) social environment was untenable, the participants indicated that a supportive family and home environment was critical. It was part of their *fortress*, a safe place to retreat to in times of stress. This property had two dimensions *providing boundaries and understanding*. When parents *provide boundaries and understanding* they were considered to be supportive. The data indicated that those participants who believed they were without affective family and home support were particularly vulnerable in moments of stress or when Being Treated Differently made their lives difficult. Where home attitudes were negative with poor levels of parental and sibling understanding about AD/HD the participants felt exposed to issues beyond their control. The following extracts from interviews with two of the participants demonstrate how some family attitudes were seen by the adolescents as detrimental to their ability to manage their own lives:

He [brother] mainly over reacts a bit. If I did something he would make it look ten times worse than what it is (WK-3, 282-283); Mum treats me differently, worse differently [since her diagnosis]. Um

²⁰ As before expletives have not been omitted or changed as they convey the participant's very strong feelings on a subject.

well now she just makes decisions by herself about me like that I need a new tutor or something like that and says right you are doing this cause you have got ADD you are going to be doing this and that is why (WK-5, 34-55).

In the first extract, WK had been expressing concern about what her brother would do to her with regard to her diagnosis. She appeared very nervous when he was around. In the second extract, she was discussing a conflicting situation that had developed between herself and her mother. Previously, decisions relating to tutoring were joint decisions since her diagnosis she was no longer allowed any input. She concluded by saying that her Mother now thought her AD/HD made her too stupid for her to become involved in the decision making process. A further example of negative home attitude is:

The other night I said (well my Dad gets pretty frustrated when I don't do my vacuuming) I said to my Mum I will just leave the vacuum here because I will do it later on. Then my Dad started "you are not going to do your vacuuming are you"? I said "yes I was going to do it". He goes "no you're lying" because he had previously said to me if I go out the night before then in the morning I am going to be all shitty and look tired and stuff and I am going to treat him badly and get agro and things like that. I wanted to prove him wrong by helping around the house and so when I said "yeh I was going to do my vacuuming" he said "no you won't do your vacuuming" calling me a liar and such stuff. I just swore at him basically. I rarely ever swear at my parents but this time I just did it. He just seemed so immature like he was acting like such a baby. I said to him "why are you acting so immaturely about this" I said "do you know I was going to do it" and he went "because I am allowed to this is my house". It just so frustrated that I swore off my head and went into my room. It just seems like such small things just tick him off. (BS-1. 159-175)

A rising level of conflict became apparent between this participant and his parents during the data collection period. The parental control evident in this

extract appeared different to that of *providing boundaries*. In this instance the participant indicated that he thought the level of control assumed by his parents bordered on authoritarian and unsupportive. That is not to say that the participant did not acknowledge the need for parents *providing boundaries*, he too, like the other participants, considered that parents *providing boundaries*, was necessary and was what *scaffolding* was all about as it signified support. In this instance, however, BS considered his Father's actions and accusations unreasonable, particularly as his parents did not assume the same authoritarian levels of control with his younger siblings. This appeared to indicate that these parents, like WK's mother, considered that their son BS was unable, because of his diagnosis, to undertake his own home tasks without them continually "getting on his back" (BS-1).

An example of why BS came to the conclusions he did, emanated from the last interview I had with him. In this interview he referred to one of his younger brother's drug taking. He was very concerned about this but felt unable to talk to his parents about it, fearing not only their reaction to him, but also not wishing to "dob in" his brother. He was also aware that the authoritarian style of parenting that he and his older brother experienced seemed to be changing for his two younger brothers "they don't seem to care what they [the brothers] do now! I don't know why perhaps they have decided to change. I worry though they don't know what they do" (BS-3 455-460).

A study by Smetana (1996) identified three patterns of family structure amongst middle-class white American families and lower-class Hong Kong Chinese families with adolescent children. These patterns of family structure were: frequently squabbling, tumultuous families and placid families. Frequently squabbling and placid families are self-explanatory, however, it is the tumultuous family that is of relevance to this research. In Smetana's study parents from tumultuous families tended towards an authoritarian style of parenting, with more rules, more restrictions on adolescents' personal jurisdiction than other families and at the same time demonstrated less warmth towards their adolescent. Also the tumultuous family was more inclined to be in the lower income bracket, divorced or remarried. Adolescents in the tumultuous families tended to have poorer levels of academic achievement. Tumultuous families were those who experienced greater levels of frequent and variable but intense conflict than other families.

Smetana's findings correspond with data that emerged from my research (with the exception of the economic status of the family). The data I am referring to is that associated with BS's family. As many of the quotations from interviews with this participant indicated there was a high level of stress and conflict in this family. I had also been made aware that the Mother had been in a situation of extreme conflict at work that led to her seeking medical assistance. BS also suggested that his parents were very supportive of each other sometimes to the exclusion of their children.

I sometimes think they care about each other more than they care about their children. They stick together on arguments whether they think they are right or wrong. My Mum always sticks up for my Dad. They stick together even if they are wrong they stick up for each other. That is when it gangs upon the child (BS-3, 505-519)

Robin (1998) suggested that increased family stress and conflict is often associated with adolescence, particularly when the adolescent has AD/HD. This often leads to parents not permitting adolescents to be part of the decision making process (as was discussed in chapter two). Barkley (1998) and Robin (1998) stressed the need for adolescents to feel that they have been listened to and understood and their opinions taken into consideration. Barkley (1998) and Robin (1998) contended that discounting the adolescent viewpoint and putting adolescents down tends to result in conflict.

Not all of the participants experienced poor levels of home *scaffolding* and support. For some, their home environment was their place of safety, a place to return to when the outside world threatened them. For them their home support came in many ways as the following composite of answers indicates:

Not having too much of a free rein. Like after my Mum had just said she believes in pretty much letting me do what I want within the guidelines of society and the laws. But I can do what I want as long as I obey the house rules and society guidelines with what a 15 or 16 year old should and shouldn't be doing and the laws. Other than that, fine. My mum believes that when you put resistance on somebody then they are going to pull back even more. If I want

something and I grab it and you have got a hold of it, if I want it what am I going to do? I am going to pull like hell to get it. I want it and now I am going to pull like hell because you have got a hold it. But you don't want me to have it so you are going to pull back. But I really, really want it so I am going to pull back so we are just going to sit pulling, pulling, pulling and never going anywhere. That is what my mum sort of believes I can do what I want so long as I am within these guidelines. Boundaries that are set. Though this was one thing we never quite got to that was setting those boundaries in definition. They weren't a straight line they were a sort of grey. I was always able to walk up to the grey area and go there. It is ahha no but I am not in the black area I am in the grey area ahah but that is who I am, I push the boundaries. That is why she put grey areas not and black and white lines. She knew I was going to step over it anyway and why put me straight into the danger zone. Why not have a buffer zone where it is not ok for me to be there, but it is not bad for me to be there (RA-1, 141-168). My Dad Cr*** said that whenever I don't take them [stimulant medication] on one day I will cop 10 days grounding. He said that was for a bit of incentive for me to take my tablets all the time. (CB-3, 51-66)

Having *scaffolding* and being supported was not just about *providing boundaries* there were other ways such as a feeling of security or acknowledging greater maturity, "they are just there", "they expect me to know now [since starting medication] specially as I am older", "they give me responsibilities now" (RB). The following statement clarifies the feeling of security that good family *scaffolding* and support provides:

I have a really close relationship with my mum. Sometimes when we have time we sit down and watch something and we might talk about it. I haven't got really relationship with my father because he is hardly there and he doesn't talk that much. I have got a brother/sister relationship with my brother and sister. They [the family] are actually the cool groovy people so they are like it is fine.

I think a couple of our family members have got ADD so it is like a generic type of thing. Yeh hey that's family I think family is meant to be there to support you and hold you up when you are not strong. (YJ-4, 407 – 415)

When levels of *scaffolding* experienced by an adolescent with AD/HD failed them they felt very vulnerable, if in consequence their self-esteem and self-confidence fell to a low level then they may, in extremis, become very depressed and even suicidal. A study by Bussing, Zima, and Perwien (2000) supported this finding. My research indicates that although AD/HD alone was not necessarily accompanied by low self-esteem, where internalised problems were present, either alone or in combination with an externalising disorder (such as depression), there was a tendency for low self-esteem. When this perception of overwhelming vulnerability overcame the adolescent, they retreated behind the walls of their *fortress*.

School Scaffolding.

Scaffolding (support) in the school environment depended on the dimensions or degrees of *changing attitudes* within the school towards any previous problems exhibited by the adolescents. This change in attitude had to come from both the teachers and the other students. Statements like those that follow were examples of the positive changes in attitude that the adolescents experienced after diagnosis and starting medication utilisation. A composite of answers on the positive side were:

Yeh she kind of did yeh she was more understanding. Before I had go to see the doctor she thought I was just a naughty kid (RB-FG-1, 340-341). I like most of the teachers at school. I had this year for my pastoral care teacher was actually my maths teacher so I could ask her maths in PCC yes that's groovy. That's good. (YJ-1, 97-136). Mrs. H. and yeh she was never afraid to speak what she thinks so if I back chat her she goes B*** stop being an idiot or something like that or she swears at me or something like that. But now she is still at me but she doesn't really mean it, it is a mucking around way (RB-FG- 1, 346-351).

When the adolescents experienced this level of support from their schools their self-esteem is raised and they feel able to make progress and to Reach for the Light. In other words, they consider they would be able to achieve their aims and goals and succeed in their lives.

A composite of statements that demonstrated the negative elements associated with lack of *scaffolding* in schools included:

...um some teachers are fine. Some they just don't get it. They just don't want to help me 'cos of what I was like (CB-1, 231-239); when you can't do something they aren't much help at school. They just say try just try it who cares just try it (CB-4, 191-193); well ummmm Mr. S tries to tell me go um...[go go where?]. ...leave school he will just say "I feel the work place is better for you" (PB-3, 498-504); but they never actually dealt with the issue they never actually dealt with why I was acting and how I was acting. I think what they did was they said. They tried to blame it on my parents they tried to say that my parents should pull the reins back in on me and I am having too much of a free rein. (RA-1, 137-141).

The last statement referred to the action of the school when the participant attempted to confront a group of bullies who were bullying her. The school blamed the parents for the child's behaviour rather than the school's inability to manage, what appeared to be, the serious bullying issues occurring in the school. According to Frank (2000), teachers varied dramatically in their ability to work effectively with students who have AD/HD. Some were very knowledgeable about AD/HD and the special difficulties it creates for children. Others, however, were severely lacking in this knowledge and their ability to implement effective strategies was limited. As a result, children with AD/HD and their parents become frustrated by the failure of the school to provide the assistance they need to be successful. My research data indicated that where *scaffolding* (i.e., support) was lacking in a school the individual required a strong sense of *fortressing*, or self-protection and the ability to *balance* conflict, in order to cope with the problems they were experiencing and to manage their lives.

Support in the form of *scaffolding*, was not solely the responsibility of the school or the family. For the adolescent with AD/HD the support of their peer group or friends was as important as it is for any other individual in society; more so perhaps, for the adolescent with AD/HD whose experience of their social environment is not always one of being supported. As my research has demonstrated those with AD/HD tend to have low levels of confidence and self-esteem. A recent study undertaken with boys by Hoza, Pelham, Dobbs, Owens, and Pillow (2002) indicated that boys with AD/HD and depressive symptoms tend to have a poor perception of themselves and lower levels of global self-worth (self-esteem) whereas, those with AD/HD without depressive symptoms did not necessarily exhibit low self-esteem. Hoza et al's findings would appear to indicate that it is not necessarily the presence of AD/HD symptoms that leads to low self-esteem, but rather the presence of comorbid depressive symptoms.

Participant DM (TS1) indicated that in her opinion, poor self-esteem was often a result of those with AD/HD being viewed as 'dumb' prior to diagnosis and that this perception tended to endure after diagnosis whatever the improvement in scholastic outcomes. This last comment by DM supports previous research by Chia (2002), Frankel et al. (1999) and Rucklidge & Kaplan (2000) and appears to indicate that poor self-esteem in AD/HD is determined by two factors. First, the physical problems experienced by those with AD/HD that leave them exposed to poor academic and social achievement. Second, there is a tendency for those with AD/HD to be treated differently by society, blamed for their deficits and marginalised. It is my contention that effective sympathetic support from those around them is, therefore, an imperative if adolescents with AD/HD are to be able to achieve their aims and goals and Reach for the Light. The participants in my research, as well as Polis (2001) and Amen and Johnson (1996) appeared to support this view.

Friends Scaffolding.

In my research the adolescents described peer/friends *scaffolding* and support in the following synthesis of answers:

...no they just see me as a normal person (CB-3, 160-167). We go around together don't mix with the others, yeh we stick together (PB-2, 336-345). When I need someone to talk to I will talk to him

he knows, most of the time he knows what I am talking about and what I am feeling and things like that. Because of that other people understand as well now. Most of my friends understand it (RB-FG-1, 350-352).

In many cases the participants were most comfortable with others like themselves, i.e., others with AD/HD. The adolescent felt disempowered when others were "being mean" or "hassling them" or failing just to "listen to them" or "not respecting them". Seeking the support of like-minded friends was, therefore, recognised as a way of overcoming these issues.

Within the context of *friends scaffolding*, *being cool* and *having friends* were significant dimensions. Cool is an elusive word; the difference between the adult concept of cool and that of the adolescent was discussed in chapter two. Pountain and Robins (2002) suggested that defining cool was an uncool thing to do for cool or coolness was one of those things not easily defined, but you definitely know it when you saw it. *Being cool* is being accepted (and included) by those around you (the peer group and/or friends) and being like others. I will leave it to the participants to depict cool. Here are some of their comments:

When they are cool that makes things all really good because people understand can actually accept that I have this disorder and can actually still stand me as a person and not and know some of the affects that make me go a bit wonky on the wonky side and think I am doing that on purpose. (YJ-4, 254-256)

For others *being cool* had different meanings. Before coming to terms with their disorder the adolescents expressed this view of *being cool*:

As a teenager I wanted to be individual, my own person. But the reality was that I wanted to be just like the others. They didn't have ADD or take medication so I didn't. Teenager pride. I later came to realise that it was better to take the medication and to succeed. This too was cool. (DM-TS1).

Cool, tended to signify that an individual was accepted by their peers and friends for what they were, then "everyone is pretty cool and [they] don't do anything about it [their AD/HD]"(CB). Cool was also doing things that did not harm others but shocked adults, like having the radio on full blast in the car with the windows down. Wearing a funny hat and so on (RA). *Being cool* was part of being accepted and included *having friends*. It is *having friends*, being able to act silly when you want. "It is that feeling of belonging so important to all individuals in society" (DM-TS1).

It is my contention that in reality, the adolescent with AD/HD is the same as any other adolescent. They want to be accepted, to feel supported, to be needed, not to be ridiculed and fearful of the way they will be treated. They want to manage their own lives to go on and have families, jobs and succeed, they want to Reach for the Light.

The significance of support, in the context of home and family, school, friends and or peers, as a part of the *scaffolding* framework for the adolescent emerged from the data as a series of differing supporting typologies; the format of these typologies and how they evolved are the subject of chapter seven.

Medical Profession Scaffolding.

The penultimate property in the category *scaffolding* was that of the *medical profession scaffolding*. For the most part, the participants considered that they experienced support from members of the medical profession. The role of the doctor, however, was seen more as peripheral to their needs rather than being located with the immediate social environment of the adolescent participant with AD/HD. In the main, the participants turned to their doctor for advice regarding medication problems, though this was not always so. On the whole, however, the participants appeared more inclined to turn to their family, friends and school for *scaffolding* and support than their doctor. Those participants who did not experience sympathetic support from their paediatrician tended to change to another specialist in search of better support. The problems that participants experienced with members of the medical profession included: being "talked down by them", or being sent out of the room while the doctor talked to their parents. This sort of action by a doctor was seen as demeaning to the adolescent and

demonstrated to the adolescent that their needs, problems and opinions were of no consequence to the doctor.

Coping Skills Scaffolding.

The last property of the category *scaffolding* is that of *coping skills*. As the participants moved through the levels of process the importance of the medication as a tool to help them to cope in their lives was emphasised more and more. As L-TS-3 states "without a good grasp of how medication can work for you – even though I hate taking it – you cannot overcome the problems. Medication and *scaffolding* are linked together". When they were taking their medication the participants indicated that they could organise themselves and develop *coping skills*. "Medication is like putting on glasses. You can see what to do, act like a normal person" (DM-TS1). The participants also developed self-help techniques many of these, however, were somewhat idiosyncratic (i.e., locking the door to the room where they were working) but in their view they worked for them. Setting routines and removing all distractions became important to the participants in order for them to achieve aims and goals. Many of the adolescent participants in my research worked with the stereo on, "so I won't get bored". Those who were hyperactive would often work late into the night. In other words they came to terms with how they could cope with being AD/HD.

In this discussion I have endeavoured to show how the levels of process that form the theory Reaching for the Light continually wove backwards and forwards as each of the levels interacted with each level of process and within itself. It was through this continual process of *seeking solutions*, *transforming*, *scaffolding*, overlaid by *fortressing* and *balancing* that the adolescent with AD/HD sought to overcome the problems they experienced in their lives and to achieve their aims and goals to Reach for the Light. None of the participants, whatever the difficulties they experienced, lost sight of their desire to achieve their aims and goals. Their delight when they received improvement certificates, achieved better assignment grades, won a long distance race (RB-3) was palpable. It was their sheer determination to prove to others and themselves that they could achieve that drove them onwards.

The final stage of the process of Reaching for the Light is that of *potentialising*. With *potentialising* the participants in my research sought to draw upon and maximise their abilities.

The Fourth Category in the Core Process: Potentialising

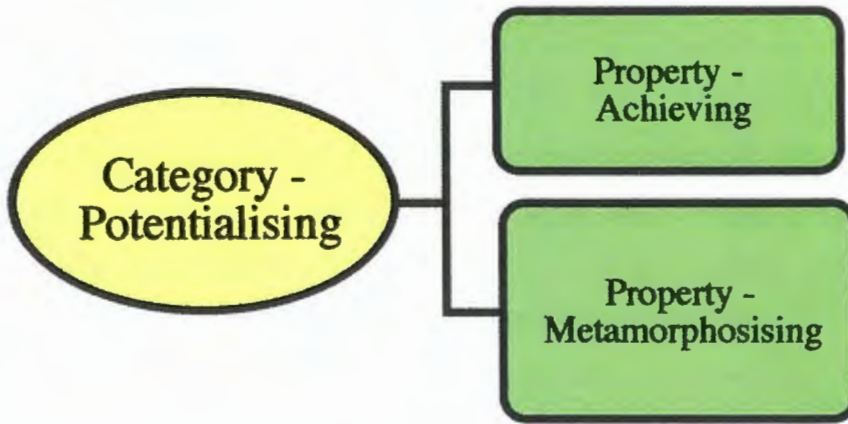


Figure 15. A Diagrammatic presentation of the category *potentialising* with its properties.

This fourth category, *potentialising* has, as Figure 15 indicates, two main properties of process, *achieving* and *metamorphosising*. With the property *achieving*, the adolescents sought to achieve their aims, goals and dreams. The process of differentiating reasonable achievable aims and goals and dreams was based on degree. For example, aims and goals could include getting a better mark with the next exam, being able to focus on a specific issue, these are all achievable aims and goals set at achievable levels. Whereas, dreams such as a trip round the world or learning to fly a plane are dreams that may happen, therefore, they are still something to aim for.

Achieving.

The process of *achieving* was progressive. With better academic outcomes such as in the following composite of answers:

Yea, now my marks were lifting and everything was going good and it was pretty beneficial (BS-1, 58-65); Just to get better so as to give me better grades. I will be able to get a better job (CB-3 66-68); get things done quicker and not so many mistakes, such as spelling mistakes and grammar. Like just grades and progress a

little bit, higher grades (WK-3, 65-66); I like computers. I can do designs and I can make cartoons... Ours is a bit slow I am used to very fast computers 'cos we have the latest ones at school (YJ-1, 10-17)

participants could plan for their future. For example:

When I leave school I want to go on to TAFE. Need good grades for this (WK-3); [I want to do a] Boilermaker welder apprenticeship or a bicycle mechanic course. [Bicycles rather than motors?] Yes bicycle bicycles. Not so much hard work. Don't have to slug your guts out. Get paid good money. Reasonable hours. It is also a trade so you are basically in it for life when you done your course (CB-4, 167-177); I want to do bachelor of commerce or commerce degree or. I read up on it. Generally I am interested in public relations or financing or banking and management. Management of people as opposed to management of funds. That would take leadership skills and which I have learnt already and things like that which I quite like as well. I learnt [people skills] through drama and work and things like that. I can see myself in the future doing things with people and also money and things like that (BS-3, 405-411); I want to be a nurse and all that. To help other people around me who are worse off than me at the most sometimes (YJ-FG2, 815-818).

Even those adolescents who had yet to reach the ultimate achievement stage of *potentialising* still planned for their future as they began to focus and concentrate on their work and achieve better at school.

What *achieving* was all about for the adolescent with AD/HD may perhaps best be summed up by this quotation from Polis when he was aged 19 (2001):

Writing this book is my greatest achievement to date. It took many long months to write and I just hope that all my hard work will help other people to understand ADD and more importantly their children, better....If I had not had my strong family support I would not have achieved anything. I would have ended up just another

statistic, a juvenile ADD person in jail....In the future I plan to write another book that focuses on how to teach ADD children and how to survive through university/college...because many [ADD students] do not reach their full potential as a result of not achieving. (p. 166-167)

Metamorphosising.

The second property in the core category *potentialising* was *metamorphosising*. *Metamorphosising*, as the Macquarie Dictionary (Delbridge et al., 2001) notes, signifies the transformation from the immature form to the mature form. By this stage in the process of Reaching for the Light the adolescent participants indicated that they had come to accept the need to reconstruct themselves in order to conform to social expectations i.e., to *metamorphosise*. Their understanding of social mores and values increased and they accepted the need to conform in order for them to be "accepted as normal people" (DM-TS1). Without exception the participants, (whether they had reached this stage of process or not) indicated that their conformity was only to the extent that each individual desired it, or perceived the need for it (DM-TS1; MB2-T2; L-T3; BS; PB; CB; RB; RA; WK; YJ).

Potentialising.

By the time the adolescents reach the stage of *potentialising* they have begun to gain confidence in themselves whilst accepting their limitations. This final stage of the process that is the core category *potentialising* was where the adolescents proved to themselves and others that they were able to manage their lives. Not all of the participants in my research had reached this final level of process during the period of data collection. Those adolescents who were yet to reach this final stage, however, were still set on achieving their aims and goals. The adolescents indicated that they were only able to reach their potential and achieve their aims and goals if they felt secure in their environment. When their world and their lives were in equilibrium the adolescents were able to move on to finally achieve their aims and goals in order to *Reach the Light*. If, however, their *scaffolding* was inadequate or not there and *balancing* and *fortressing* did not resolve the vicissitudes of life then they felt vulnerable.

It was at the point of *potentialising* that the adolescent with AD/HD has come to terms with themselves and their world around them. Each individual had come to accept the need to take medication and had a good understanding of how the medication worked for them. "I irritate myself when I am not on my medication" (DM-TS1; RA). Without exception, the participants indicated that without the ability to focus and concentrate that came with medication utilisation they could not *transform* themselves to meet social expectations or build their *scaffolding*. The participants made it clear that they hated taking the medication. They also indicated that they considered that the length of time taken to 'come to terms' with their medication had cost them a lot in relation to where they were now in their lives. The participants suggested that if they had appreciated why there was a need to continue their medication in previous years they would have experienced better academic outcomes, i.e., better TEE results. This was particularly so of the high achievers who were always "chasing the carrot of life"(DM-TS1).

Those participants who had reached the stage of *potentialising* expressed the view that until all the levels of process were established they could only seek to Reach for the Light but in reality could not achieve this all encompassing aim because Being Treated Differently was a significant factor in their lives. The adolescents also expressed the view that those with poor social skills or those who were unsure of themselves were more likely to be adversely affected by the problem Being Treated Differently and resented this.

The following statement expressed the way one participant felt about how she had come to this stage of her life and why and how she believed she was able to achieve her aims and goals:

I look at who I am today. The views that I have and the opinions that I hold and the way that I think and understand people and I like that. I know I wouldn't be the same person if all the things that have happened to me in the past hadn't happened to me. Because what happens in the past helps to shape and define who you are and who you become. I am grateful that I can sit here and think about everything I have just said to you and tell you that I believe 100% in everything that I have just said. It is what I believe and what I think. It is me. It is my way of thinking, my way of seeing the world. It is

my belief. It is true. It is not the Dolly magazine says wear this, say this and then the boys will like you. Because I had that problem with people liking me. For as long as I can remember me doing something, saying something, thinking something so that people will like me has never been an issue. It was people don't like me they are never going to like me so why should I care. Because whatever I am going to say or do will make them not like me. That kept me very true to my self. I didn't get swayed by peer pressure or idealistic views. I went hullo, what do I think about that? Right that is what I think about it. Not Felicity thinks that and Sally thinks that and Sally has lots of friends so she must be right. (RA-1, 403-422)

All three of the second group of adolescents to join the study who took part in the theoretical sampling stage of the data analysis had reached this final level of process *potentialising*. Three of the initial group of seven participants had also come to the stage of *potentialising*. The remaining four had yet to adequately secure their *scaffolding* and were still experiencing problems. Their desire to Reach for the Light and achieve their aims and goals was, however, still as strong, as the following statement by one of these participants indicated:

This is my life, hey why do I have to go back to school because I want to get an education. I am in year 10. I can stay this year and then decide where I am doing the rest [may be] in TAFE except I really want to do nursing so that means I have to go through to year 11 and 12 so yeh I have to go on. To prove myself. (YJ-4, 227 – 229)

Outcomes

The outcome of my research with a group of WA adolescents diagnosed with AD/HD was that they managed their lives by Reaching for the Light. Whether they are able to achieve the four levels of process that emerged from the data or whether they are always striving to Reach for the Light will depend the adolescents coming to terms with a number the following issues.

- 1) With the first level of process *seeking solutions* the participants in my research began to understand their problems and the symptoms they were experiencing. At the culmination of this stage the adolescent with AD/HD had come to appreciate that their medication enabled them to focus and concentrate on what they were doing or trying to achieve. With increased focus and concentration the adolescent with AD/HD was able to moderate their behaviour so that they conform to social conventions.
- 2) In the second stage of the process *transforming*, the adolescents began to develop insights about themselves, particularly in the context of their disorder. They also began to comprehend how social action and interaction is determined by the conventions of culture and to put this knowledge into effect to try and achieve equilibrium in their lives. In other words they began to realise how and why conforming to social mores, values and expectations allowed them to participate equally and with comfort in their world and to begin to manage their own lives.

Stimulant medication was a significant issue for the adolescents with AD/HD as it brought with it social criticism. After *testing* the veracity of their stimulant medication, however, they came to accept that stimulant medication had a role to play if they were to be able to achieve their aims and goals and to manage their lives. The participants also noted that accepting the need for stimulant medication came with increased maturity. One participant indicated that maturity also allowed her to no longer feel ashamed of being AD/HD. As other studies have indicated careful titration of medication is as important for adolescents with AD/HD as it is for younger children. Only with careful titration can appropriate stimulant medication levels be determined that maximise the benefits and minimise the negative aspects of the medication. It emerged from the data that the assumption that 'the adult knows best' is not always applicable with adolescents, if they were to accept the need to take the medication and to continue to ingest it. The adolescents' involvement in conjunction with the adults in their lives (doctors and parents) in the decision making process with regards to stimulant medication usage was more likely to bring about positives outcomes. Without the adolescents'

involvement in the decision making process about their lives strategies aimed at improving social and academic outcomes are unlikely to succeed.

- 3) The third stage of the process *scaffolding* highlighted the adolescents' need for secure frameworks in their lives. This *scaffolding*, which was their protection against the inconsistencies and confrontations in their lives, came from their family, their teachers and their friends and peer group. Without adequate, effective non-confrontational levels of support from their social environment, adolescents with AD/HD were more likely to have poor social and educational outcomes and may become depressed, or even resort to attempting suicide, however, much they try to Reach for the Light.

The association between levels of self-esteem and internalising disorders, such as anxiety or depression, was a significant factor in my research, particularly with female participants. If levels of self-esteem for those with AD/HD and comorbid depression are to be improved then there is a need for further research in this area.

- 4) The fourth stage in the process *potentialising* was not one that was achieved by all the adolescents with AD/HD who participated in my research. This final stage may only come together when the adolescents have transcended and secured the previous three stages *seeking solutions*, *transforming* and *scaffolding*. Then and only then, did the adolescents consider that they could achieve their aims and goals and may be even their dreams and Reach for the Light. This stage required the total metamorphosis of the individual from a difficult, often confrontational individual with many problems to one who accepts that for their lives to be in a state of equilibrium they must fully comprehend themselves and their world and all the ramifications that such understanding brings. Until this point and pending the adolescents being able to overcome the many problems and issues in their lives they are beings in transition always seeking to Reach for the Light.
- 5) A greater awareness of the needs of the adolescent with AD/HD, particularly as they relate to strategies to assist them to cope with their problems is required

from both parents and teachers. For example, it emerged from the data that some parents considered that a diagnosis of AD/HD rendered their adolescent incapable of managing their lives. These parents tended not only to 'not let go of the reins' but also to adopt a more authoritarian approach to their parenting style, rather than helping the adolescent to come to terms with their problems and cope with them. This was despite the efforts of their adolescent to conform to social conventions and to begin to take charge of their own lives.

Conversations with the participants also demonstrated that teachers tended to the assumption that a diagnosis of AD/HD rendered the adolescent incapable of useful involvement in the school community. This attitude was very damaging to the adolescents' self-esteem and academic outcomes.

- 6) A significant issue discussed by the participants related to their concerns with regard to the media and its influence on society and the way in which media reporting directed social action and interaction towards those with AD/HD. Media driven moral panic, particularly in relation to stimulant medication, coloured social perceptions of AD/HD and adversely affected both those with AD/HD and their families.
- 7) It is my contention that the adolescents demonstrated their maturity when they sought to overcome problems such as these through the processes of *balancing* and *fortressing*. The overlay and interaction of these two near core categories was the way in which the adolescents with AD/HD came to terms with the many issues and problems in their lives and sought to manage their lives to the best of their abilities.

Chapter eight will further discuss the research outcomes. First, however, there was one final area of influence to emerge from the data analysis. This area of influence was that of Typologies of Support (depicted in Figure 6 as Area 3). It was discovered during the data analysis that a secure framework (*scaffolding*) in the form of patient, positive, uncritical support was necessary for an adolescent to be able to fully achieve their aims and goals and Reach for the Light. It emerged from the data analysis, however, that there were four different levels of support available to the adolescents in my research. These Typologies of Support are now the subject of chapter seven.

CHAPTER SEVEN

Typologies of Support

An outcome of my research was the discovery of a 'grounded typology' (Glaser, 1978) that defined the social supporting units available to the adolescents with AD/HD who participated in my research. According to Glaser, a grounded typology is a concept-indicator model based on differentiating criteria that are earned distinctions and not received distinctions. The criteria or concepts that emerged from the data were the dimensions or levels of support available to the participants. For a type to earn its place in a study as a grounded typology it must make a difference in relation to other categories (Glaser, 1978). For example chapter six identified that there were five areas of an adolescent's environment that form their *scaffolding* which was a significant category in the levels of process. As the data analysis progressed it became clear that having support was not only part of the participant's *scaffolding*, but that the level and type of support available to each adolescent influenced all the other categories in the process Reaching for the Light. Whether a participant was able to achieve their ultimate aims and goals and how far they could progress towards this was, therefore, contingent upon the level of support they experienced from their social environment at all levels of the basic social-psychological process.

The 'grounded' supporting typologies that emerged from the data describe and explain the types of support structure available to this small group of adolescents as they manage their lives. Each Typology of Support takes into account the specific level of support from their social environment and the impact or influence that level of support has on they way in which they are able to manage

their lives. The data in my research also revealed that the level of support available to each individual determined not only how they were able to manage their lives but also contributed to outcomes associated with self-esteem, risk-taking behaviour and levels of both academic and social achievement.

As chapter six presented extracts from the data to demonstrate the thinking of the participants I do not intend to repeat this in chapter seven except to clarify a position or concept. The role of chapter seven is to identify and describe the varying levels of support that were available to the adolescents who participated in my research.

The four distinct typologies that emerged and their relationship to the levels of process are documented below. First, Figure 16 presents a diagram of Typologies of Support. Typologies of Support were shown in Figure 6 (chapter five) as Area 3:

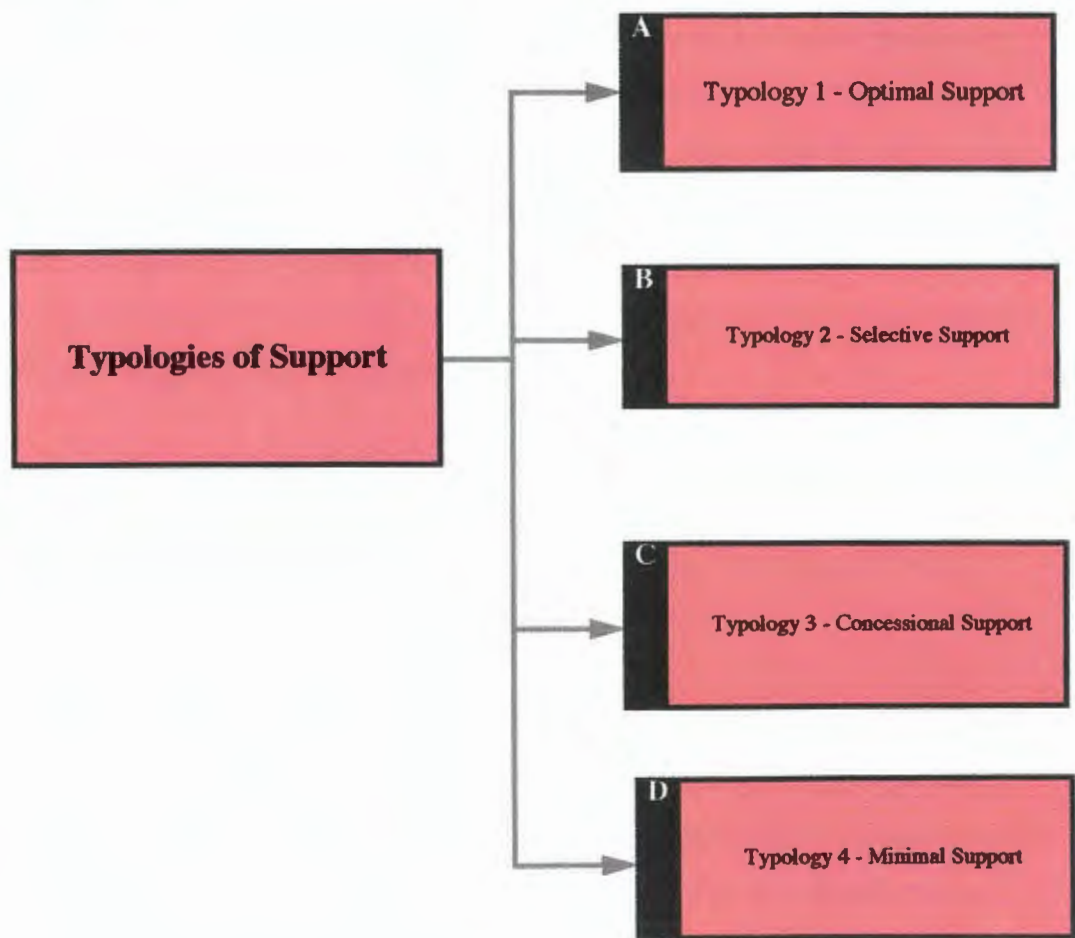


Figure 16. A diagrammatic representation of the Typologies of Support with the four different levels of support.

Each of these Typologies of Support will now be discussed individually.

Typology One: Optimal Support

Within this typology the adolescent participant with AD/HD was fully supported in all spheres of their social environment i.e., their family, their school, their peers/friends and their doctor. The participants indicated that once they had established a rapport with their doctor, this doctor's support of the adolescent was enduring, even if changes occurred in their supporting environment in relation to family, school and peers/friends.

The experience of the participants with Optimal Support was that of patient, positive and understanding attitudes from those around them. Those adolescents who experienced Optimal Support exhibited a higher degree of self-esteem than those whose support is less than positive. The outcomes of my research suggest, therefore, that an adolescent experiencing Optimal Support may reasonably expect positive outcomes relating to self-esteem, risk-taking behaviour and improved levels of academic and social achievement. The participants in my research with Optimal Support indicated that they consider they were able to progress through the stages of Reaching for the Light with minimum distractions. Where they encountered problems their high level of support and positive self-esteem assisted them to adapt their lives in order to overcome these problems, either by developing new strategies or by circumventing problems. An example of a circumventing strategy is as follows:

I have never been able to read books. I have always had to be doing something different, like be active and on the Internet. When I building something [I was made aware that he is very good at metal work] I use pictures. (CB-2, 327-329)

This example also illustrates how those with AD/HD may more often be engaged not in the goal of learning, but rather, in managing their own intrinsic problems and identities when reacting to situations. In this extract not only was CB circumventing his reading difficulties, but at the same time by following the pictures rather than reading the text he was protecting himself by carrying out a task in such a way that others are not aware that he has a reading problem. This thinking was also recognised by Reid (1998) in his discussion relating to students with learning difficulties. According to Reid (1998), school students who

experienced learning difficulties are both adept and motivated to use strategies frequently regarded as non-productive in the service of 'passing' or achieving their own ends.

Sociologists refer to the basic processes of developing a sense of self, as individualization (Cote & Schwartz, 2002). According to Cote and Schwartz (p. 573), individualization as a process of identity formation "refers to the extent to which people are left by their culture to their own devices in terms of meeting their own survival needs, determining the directions their lives will take and making myriad choices along the way". This would certainly appear to be the case for those with AD/HD. As chapter six revealed, those with AD/HD not only have to come to terms with their diagnosis and medication usage but also transform themselves to conform to social conventions. At the same time, they have to cope with the media driven culture of fear relating to the disorder that influences social attitudes towards those with AD/HD. Cote and Schwartz indicate that the process of individualization brings with it significant problems, particularly for those not equipped to handle adequately the pressures that come with the process. For the adolescent with AD/HD who is Reaching for Light positive, patient, understanding supporting structures are, therefore, of vital importance. The adolescent with a positive affirmative Optimal Support from their social environment is able to reflect on relationships with others, constantly trying to plan ahead; make life-altering choices and take responsibility for personal failings and limits, while coming to terms with the social labelling associated with AD/HD. It is argued that those adolescents with AD/HD who experience affirmative Optimal Supporting attitudes from their social environment are, therefore, better able to develop a sense of self, that sanctions them to achieve their aims and goals.

Typology One: Optimally Supported, was the experience of five of the participants (three male and two female) in my research. Although one female experienced a degree of family conflict associated with her diagnosis, in the main, her family provided a reasonable degree of support. According to these five participants the relatively high level of support and the positive attitudes relating to their diagnosis and stimulant medication usage that they experienced from their social environment (i.e., family, school, peers/friends and doctor) in their view ameliorated, to a large extent, the basic social problem Being Treated Differently and gave them the confidence to overcome not only their epistemological problems

but also their experiential problems. The viewpoint of these five participants is supported by a recent study by Olsson, Bond, Burns, Vella-Broderick and Sawyer (2003) which noted that with the development of a positive self-concept individuals were able to achieve reasonable life outcomes despite the presence of differing adversities.

During the data collection and analysis process, these five participants exhibited reasonable to good levels of self-esteem and indicated that they were achieving, or would be able to achieve, their aims and goals. It was these participants who had achieved the core category, *potentialising*, as discussed in chapter six.

For those in typology two the experience was somewhat different.

Typology Two: Selective Support

In this typology the adolescent with AD/HD may reasonably expect support to be forthcoming from their family and peers/friends with ongoing support from their doctor. Support, however, did not emanate from the school environment. Or at best was minimal; for the most part, the participants' school experience was that of negative attitudes from teachers and other staff members where the family was often blamed for the adolescent's problems i.e., behaviours.

The data indicated that those participants who experienced this level of support from their social environment had lower levels of self-esteem and tended to demonstrate inferior social and academic outcomes than those with Optimal Support. The data also pointed to higher levels of anxiety and depression for the participants experiencing Selective Support. Despite their less than holistic level of support, however, the participants in my research continued to try and achieve their aims and goals. The link identified in my research, between self-esteem, anxiety and depression for those with AD/HD accords with the views of Bussing, Zima and Perwein (2000). They suggested that AD/HD alone does not appear to be associated with lower levels of self-esteem in school-age children. Rather, low self-esteem was more likely to exist in the presence of co-occurring internalised problems. Bussing, Zima and Perwein's study found that 30% of those with AD/HD and comorbid internalising problems, such as anxiety and depression, tended to have low self-esteem. In chapter six it was noted that during the data

collection process participant YJ was diagnosed with comorbid depression. For the three participants who experienced a negative school environment with little or no support forthcoming from this area, their sense of identity was less secure. This corresponded with Cote and Schwartz's (2002) view that self-individualization was more difficult for those who experienced outside pressures that they are ill equipped to handle. It is argued that where, as in the case of these participants, the school attitudes towards them and their disorder were less than positive then their academic outcomes were likely to be compromised. Frank (2000), Rief (1993) and other scholars in this field argued that there would appear to be a need for further education and training of teachers related to AD/HD if better academic outcomes for those with AD/HD were to occur. The extracts illustrating negative school and teacher attitudes highlighted in this and the previous chapter also attest to the need for further teacher education. Without the knowledgeable support of teachers and the setting up of effective coping strategies for those with AD/HD, the future outcomes for these individuals is less than positive. As the negative attitudes of teachers and other staff members recounted by the participants were presented in chapter six, I include only one further example here:

Well, my last teacher she like treated me worst when she found out. She treated me worse. Like um I could ask her what I had to catch up on and she wouldn't tell me. So I couldn't catch up on it. (PB-FG-1, 317-318)

Although the participants in this group (Selective Support) all had the support of their family and friends it became apparent that at times even this support tended to be qualified. For example, the extract from RA (p. 232-233) discussing her feelings of hurt over her boyfriend's attitude with regard to her medication indicates a lack of support in an area where support had previously been forthcoming. The data revealed that when a previously supporting social group adopted a negative attitude then that adolescent participant tended to resort more often to *fortressing* and *balancing* in order to manage their lives. Moreover, the data also illustrated that where a participant experienced a high degree of negativity associated with both their disorder and stimulant medication usage from their social environment they appeared to become more depressed and that this depression seemed to compromise a participant's level of self-esteem. The more

compromised their level of self-esteem the more the participant resorted to *fortressing*.

The higher level of depression and anxiety reported by the participants in this group and the following two groups as opposed to those in typology one was of concern in my research as depression appeared to be associated with increased risk-taking behaviour. For example, attempting suicide or substituting stimulant medication for other drugs. It was interesting to note that it was the participants in this group who asked more often for advice relating to their problems or for literature on subjects such as stimulant medication. As previously mentioned, at the participants' request I lent two of them a book by Ben Polis (2001), which they then gave to their parents to read. It was this group who appeared to gain most from the realisation that they were not the only ones with the problems. The three participants in this group, after expressing initial fears about talking with others, responded favourably towards the focus group meetings. One participant, despite the data collection period ending, still rings for support and information when he has the need.

To summarise, the three participants (two male and one female) in my research whose supporting framework was modelled on Typology Two: Selective Support had lower levels of self-esteem than those who experienced Optimal Support with depression and anxiety becoming real factors in their lives. The mainly experiential problems these participants encountered in their social environment (particularly their schools) led to them constructing stronger barriers (*fortressing*) around themselves, they spent a considerable portion of their day trying to *balance* their lives and *manage the conflicts* they were experiencing. Only one participant, a male, due to the encouragement of his family and friends had reached the stage of *potentialising*. The other two were still trying to establish strong *scaffolding* to protect themselves from adversity and the hostile attitudes of some in their social environment. These two participants indicated that it was more difficult for them to Reach for the Light. Instead, they continually moved between the processes of *transforming*, *fortressing*, *balancing* and *scaffolding* as they endeavoured to meet the expectations of their social environment while continuing to try and manage their lives.

Selective Support and the next typology, Concessional Support, while being similar to each other in outcomes, were distinguished by the differences in their supporting agencies. The uniting factor associated with these two typologies was that the family remained the main supporting unit for the adolescent participants. Where typology 1, Optimal Support, may be regarded as the ultimate desired level of support for an adolescent with AD/HD, typology 2, Selective Support and typology 3, Concessional Support were of an inferior level. With these two typologies there was evidence of a lesser degree of support. In other words, the participants experiencing either of these levels of support did not have holistic support from their social environment. As chapter six revealed when the level of support the participants' experienced was compromised by the negative elements in their lives then the outcomes relating to levels of self-esteem, risk-taking behaviour and academic and social achievement were worse for those adolescents.

Typology Three: Concessional Support

Where this Typology of Support was available to an adolescent with AD/HD it was support at a reduced level to that of the previous typologies. Support in typology three was still provided by the participant's family and their doctor and both the family and adolescent may have been further supported by outside agencies such as counsellors, psychologists, or Youth Focus. Support was unlikely to be forthcoming from their school but in addition support was only available on occasion from their peers/friends. Only one participant was identified in my research as experiencing typology three. The majority of participants in this research experienced greater levels of support; albeit that for those with Selective Support had a lesser degree of support than those participants with Optimal Support. It was also noted in the data analysis that it was the female participants in typology two and three who experienced the high levels of in-school bullying discussed in chapter six. Up to 60% of children aged eight to 18 have experienced either physical or verbal bullying (Allen, 2002). The victims were often passive or submissive or disliked by the peers (Rey, 2002). The implications for the victims of bullying were that where it was combined with low perceived control on the part of an individual it became a psychological risk factor that resulted in them being at greater risk for emotional problems and distress (Rucklidge & Kaplan, 2000). This perception was supported by Gadzella (1994) who stated that whether an

individual perceived they had control or not greatly influenced levels of stress, while at the same time affecting physical and emotional illness (Thompson & Collins, 1995). A study by Rucklidge and Kaplan (2000) reported that young women with AD/HD symptomatology reported feeling less in control when faced with difficulties as a child and viewed their childhood relationships with their parents, schools and peers more negatively than the non AD/HD child. According to Blachman and Hinshaw (2002), girls with AD/HD had more difficulty with relationships (particularly amongst their peers) than those without AD/HD and their relationships with others tended to be more unstable and include more negative features. Their study concluded that social difficulties may play an important role in negative developmental outcomes for many girls with AD/HD. This was demonstrated in chapter six when discussing YJ's poor self-esteem and attempted suicide. It was noted that her low level of self-esteem appeared to be a result of her social experience at school, rather than her AD/HD. It is argued, therefore, that where the supporting environment is less than universal it can add to the problems being experienced by those with AD/HD.

With the reduced level of support available to participants in typology two and particularly typology three, compared to those participants who experienced typology one – Optimal Support, so the levels of depression and anxiety appeared to escalate and the discussions with these participants began to centre more on their feelings and perceived lack of self-worth. As with those participants in typology two so too this participant with Concessional Support continually moved backwards and forwards through the categories of process of *transforming*, *scaffolding*, *balancing* and *fortressing* as she sought to manage her life by managing the conflict in her life and *transforming* herself to conform to social mores, values, expectations and conventions. It was this participant who had several times attempted to commit suicide and talked often of the dark side of her life growing and covering the sunshine. As the following extract shows, however, despite the negative experiences with her social environment this adolescent participant with only Concessional Support to help her still sought to achieve her aims and goals. "Doing as high as you possibly can, giving 100% most of the time and just keep on going through the tough times and the good times" (YJ-2, 453-454).

It was this participant who, when asked her aims and goals, said she wanted to be a nurse and to go and help those in Africa who had so much less than she had. Her description of what it is to feel supported was previously presented in chapter six and exemplifies the thinking, not only of herself, but also that of the other participants:

The picture is like this. The picture is cut in half. The one side is rain, pouring rain and the other is sunshine and you can go there and be happy lots of support. Whereas, all the black and the rain is dark side is like no support, bad support all that and you just feel like you are completely muddled again. But on the happy side it is sun shining and you are happy, you are confident about being yourself and all the good support around you. (YJ-4, 457-462)

The final typology to be discussed in this chapter is one of Minimal Support.

Typology Four: Minimal Support

Typology four was the least supporting environment experienced by the participants to emerge from the data analysis. In the first three typologies family support was identified as being probably the most crucial form of support for an adolescent with AD/HD, as it was the family who helped to construct and maintain the *fortress* that protects self, in other words the *scaffolding*. For the typology of support for an adolescent with AD/HD to be accorded the title Minimal Support there must, therefore, be on-going problems in the most influential areas of social environment for the adolescent. In my research, as with the previous typology, only one participant encountered this level of Minimal Support.

In this typology, for the most part, the adolescent's support emanated only from school staff and to a small extent from his peers/friends. It emerged from my data analysis that an adolescent experiencing typology four is liable to encounter high levels of conflict within the family, with support being either withheld or subject to authoritarian controls. The data analysis indicated that where family conflict ensues and if this conflict is of a high degree then there is the likelihood that the adolescent will have poor social outcomes and indulge in greater risk-

taking behaviour, particularly if the adolescent-parent conflict is due in part to the adolescent's usage of stimulant medication. Moreover, there was evidence that with Minimal Support, there was a tendency to conflict in peer/friend relationships, again associated with stimulant medication as the enduring social perception is that stimulant medication is an illicit drug. The adolescent had, therefore, lost what in general was regarded as the most important supporting structures in their world. As with typology three the level of risk-taking behaviour adopted in order to gain the approbation of others, particularly of friends, may well be the determining aspect of how well an adolescent diagnosed with AD/HD, who is experiencing this *minimal* level of social support, is able to manage their life. Being cognisant of the connection between risk-taking behaviour, such as suicide or possible medication substitution and negative social support, is important, for those involved with adolescents with AD/HD particularly, if the adolescent ceases taking the stimulant medication that may assist them with their concentration, focus and impulsive behaviour.

In the context of typology four it is appropriate to enlarge on the reasons for the adolescent-parent conflict and the damage that can occur when this conflict is not resolved. The conflict between the participant with Minimal Support and his parents was discussed at length in chapter six. With this in mind only a few brief extracts are included here to further demonstrate the association between parent-adolescent conflict and authoritarian control and the possible outcomes of this conflict:

Pretty much they would rather I didn't make my own mistakes. They would rather I went through life and made as little mistakes as possible by them telling me everything there is to know. They think teaching is better than me making my own mistakes. I think I would rather make my own mistakes and find out for myself. They don't like that. They see making my own mistakes as an increase of freedom and they don't want me to because it reflects on them [if he makes a mistake] and they don't want to have something that reflects on them. (BS-3, 350-355)

The thinking behind this extract may be considered to be the actions of over protective parents with adolescents whether that adolescent has AD/HD or not. If it

is put in context of the other discussions relating to these particular parents and the conflict with their adolescent, however, it is argued that this last quotation serves to emphasise their authoritarian style of control. Moreover, the parents went on to indicate to the participant that they expected him to find a job as soon as he had completed his TEE exams:

Well soon as I finished school my parents are saying now that you are doing nothing you have to get off your arse and do something. So I have to find something to do. I wanted to relax for a while and they said get off your arse. I said no I want to relax for a while. They say if you don't get a job we will get you one so you get out of this house. Which makes me feel they are trying to kick me out which is not a nice feeling. (BS-3, 358-380)

This story was much more complex than perhaps these and the previous extracts in chapter six demonstrated. It was not only the words that were being said but also the very real distress that emerged during the interviews with this participant, coupled with his increasing depression that drew me to conclude that this was a highly complex family with intricate relationship problems. This participant had the view that his parents wanted to control him all of the time and to not allow him to make decisions for himself. He reflected on these obstacles and was trying to overcome some of the problems by complying with his parents' requests. The participant had, however, already contravened their wishes when he chose to visit the paediatrician on his own (he was 16 years of age) to discuss his on-going problems in the home and at work and in school. The problems he discussed with the doctor related to poor organisation at school, such as not completing homework on time and poor general focus, in particular poor concentration and focus during exams. It was his perception that not only where these problems of poor focus and concentration impacting on his schoolwork, but more specifically his academic outcomes i.e., exam results. He expressed concern that his inability to focus and concentrate would compromise his TEE exams and his ambition to go to university. His poor concentration and organisation not only caused conflict in the home, but also affected his work so that he was concerned he would lose his position and compromise his ability to save for his proposed stay in England. At the paediatrician's suggestion the participant chose to trial stimulant

medication to assist him with these problems. When he was initially diagnosed with AD/HD-PI some years previously his parents had declined stimulant medication and continued to do so despite the problems that their son had been and was still experiencing at school. By this participant choosing to trial stimulant medication he was going against his parents wishes and was somewhat distressed about this. He, therefore, ceased taking his medication on several occasions during the data collection process to see if he could cope without it, but he could not and he recommenced stimulant medication usage and continued until he finished his TEE exams. On completion of his TEE exams, however, it would appear that he substituted his medication with marijuana. The participant's reasoning for this substitution was that society (in particular his peers who also castigated him for using stimulant medication calling him a 'druggie') did not consider marijuana a dangerous drug. If, therefore, marijuana assisted his concentration and focus he could at least achieve his friends' approbation and not their criticism and with their support he would be better able to manage his life.

It appeared from the data analysis that the high level of control, that was the parenting style in this family, may have contributed to the rising levels of conflict that became obvious during the data collection and analysis process. This view is supported by Robert (cited in Robin, 1998)), who suggested that:

Dominating or overly controlling parents have high expectations for obedience and perfectionism from their children and do not give any explanations for their unilateral rules; their teenagers may become angry and aggressive, rebellious and disrespectful of authority. (p. 301)

The parent-adolescent conflict coupled with the poor peer relationship may also have contributed to this participant's depression and the issues related to the stimulant medication. Although, the feelings described in the extract below may be similar to those of other adolescents with regard to lack of money etc. , in this instance this participant had for some time been talking about his feelings of anxiety and depression. He had also informed me that he had discussed his feelings of depression with the paediatrician who had proffered some suggestions to assist him. The conflict with his parents appeared to be exacerbating the problem.

Yes when I am physically sick [he was describing his feeling of depression] it brings my emotion down like things are ganging up on me or just little things like work troubles or no money any more or I can't go out with my friends. Things like that just make me feel really depressed and I want to lay in my room. When I do that my parents come and whinge about my getting a job and getting out of the house and it builds up and builds up and sends me further down in a spiral. (BS-3, 522-531)

While accepting that parent-adolescent conflict does occur particularly when AD/HD is present (Barkley, 1998; Robin, 1998) when this conflict was put in the context of the participant's visible distress at not being able to please his parents in conjunction with the tone of his Mother's communications with me after he left for England then it would appear that there were significant relationship problems in this family. These relationship problems appeared to be impacting on this participant's behaviour, particularly risk-taking behaviour and his social outcomes.

Typologies of Support, the Social Environment and Adolescent Achievement

The four Typologies of Support establish that the immediate social environment that surrounds an adolescent with AD/HD is not only influential in their development, but also makes a significant contribution to future outcomes and has an impact on that adolescent's success in later life. Adolescents with AD/HD, like other members of society, are dependent on their supporting networks to affirm their position in society, to provide positive support, particularly when problems arise and to enhance an individual's feelings of self-worth.

The family particularly, as the different typologies show, is uniquely placed. When the family is seen as supporting and presents as positive, patient and understanding with rules and boundaries for the adolescent, a partnership develops between parent and child. The adolescent with AD/HD then feels safe, supported and secure (i.e., their *fortress* and their *scaffolding* are established) and is able to progress on to take responsibility for themselves and manage their own lives.

Where the parenting style is restrictive and associated with negative parental attitudes, then depression and moodiness may be the outcomes for the adolescent, along with under achievement in life. In a series of articles discussing personality, identity development and parenting in adolescence Meeus, Silbereisen and Nurmi (2002b) conclude that developmental outcomes for adolescent are associated with first, the level of identity formation in an individual and second, whether that individual has an adaptive personality in conjunction and second, with parenting style and the parent-child relations. There are indications that those who exhibited good levels of identity development, i.e., good self-esteem, are more likely to succeed than those who had poor self-esteem.

According to Smetana (1996, p. 4) moderate adolescent parent conflict within a supporting family environment was “functional for adolescent development and relationship changes”. Adolescents from families with a significantly more authoritarian style of parenting may be more at risk of developmental disturbance and risk-taking behaviour. In Smetana’s opinion, research has indicated that the intensity of conflicts and lack of conflict resolution contributed to the likelihood of adolescent dysfunction over time. Correspondingly, Smetana (p. 35) noted that her study also found that adolescents from authoritarian families were “more oriented towards friends as legitimate authority sources for multifaceted issues than were other adolescents” (as was demonstrated by the participant in typology four). It was Barkley’s (1998, p. 434) position that “extremes of authoritarian control ... are not effective with ADHD adolescents and although parents need to continue to structure situations and maintain ultimate control, they need to increase the involvement of the adolescent in decision making whenever feasible.” As B.H. Smith, Pelham, et al. (2000) pointed out:

Most adolescents with ADHD who are under the protective umbrella of parental decision-making will eventually be young adults making decisions more or less independently. These vulnerable individuals need to be prepared to act in their best self-interest and being able to meaningfully participate in decision-making regarding treatment for ADHD may be an essential survival skill. (p. 496)

Peer relationships are also influential in adolescent outcomes. My research supports the idea that security of peer attachment allows for exploration of relational development domains. When peer attachment results in a sense of being supported, with good relationships that allow the adolescent to undertake self-exploration, as in the case of those in typology one, positive identity development will occur and high levels of self-esteem will be the outcome, along with achievement. Where peer attachment is more diffused and negative then identity development and levels of self-esteem of the adolescent will be affected. According to Adams (2000), Erikson's theory of psychosocial personality development suggests that where an adolescent has yet to form stable personal commitments but is engaged in self-exploration, as with the participant BS (typology four), then they are likely to be more anxious and variable in behaviour.

Research indicates that low self-esteem can be associated with identity confusion; whereas, positive identity formation is related to "self-certainty, social- and self-assurance, psychological confidence and a sense of well-being" (Adams, 2000, p. 73). The Typologies of Support that emerged in the data analysis sustain this notion while re-emphasising Vygotsky's thinking that human consciousness and human behaviour and interaction are shaped by cultural settings and historically bound social relations. As Blumer (1969), in his theory of symbolic interactionism, concluded the self is a reflection of the world around one. It is the self that interprets this world and reinvents this interpretation in its own form. It is the self that emerges from the social and cultural interaction. The way in which the social environment interacts with self and how self copes with this interaction will determine the level of achievement of that individual, their feeling of self-worth and the way in which they are able to manage their lives.

Chapter seven shows the affect of the four different levels of support available to the adolescents with AD/HD participating in my research that emerged from the data analysis. In discussing these typologies of support, this chapter has moved away from the central focus of my research. Nevertheless, chapter seven is deemed appropriate in that it presents a significant new facet that emerged from the data that further illustrates the differing nature of the problems the adolescent participants encountered. These problems included not only the epistemological and experiential issues discussed previously but also the not inconsiderable problems the participants encountered with their levels of support from within their

social environment. Nonetheless, in spite of these problems, all of the adolescent participants in my research still continued to Reach for the Light. Whether the participants reached their *potential* or not, they still endeavoured to manage their lives, by seeking support, autonomy and equality from their social environment in the face of Being Treated Differently.

Typology Summary

The extent to which the adolescent with AD/HD is able to achieve their aims and goals and manage their lives is dependent upon the level and degree of support they experience from their social environment. These levels of support emerged as four distinct typologies ranging from Optimal Support to Minimal Support.

Typologies of Support and the Substantive Theory: Reaching for the Light in Summary

The substantive theory model that emerged from my research is composed of four levels of process and two near core categories interrelating as they pass through stages. The group of adolescents diagnosed with AD/HD in WA who participated in my research managed their lives by means of the basic social-psychological process Reaching for the Light. The levels of process discovered from the data that enabled the adolescent participants with AD/HD to manage their lives and to Reach for the Light were; *seeking solutions*, *transforming*, *scaffolding* and the core category *potentialising*, assisted by the near core categories *fortressing* and *balancing*. Reaching for the Light epitomised to the adolescents their desire to achieve their aims and goals (*potentialising*) and manage their lives. They saw the process of Reaching for the Light as culminating with them becoming autonomous beings in an equitable world. During this process the adolescents socially reconstructed themselves to meet social expectations; they learnt how to come to terms with their medication and the views of those around them and they adapted their lives to meet problems they encountered. To do this the adolescent participants systematically constructed new lines of action to interrelate with their metamorphosising new selves.

For the human individual managing one's life is all about coming to terms with and coping with problems and issues encountered and about organising self to fit in with one's social environment. In my opinion, the levels of process that the adolescent participants employed demonstrated that they had a clear understanding about how to direct their lives. They were aware that not only did they have to reconstruct themselves to meet social expectations and perceptions but also that their *scaffolding*, as supporting frameworks in their lives, were critical if they were to be able to manage their lives effectively. Although *scaffolding* was an integral part of the basic social-psychological process employed by the adolescents it became clear in the latter stages of the data analysis that there was yet another area that influenced their ability to organise and direct their lives. Typologies of Support as social units of support emerged as this area of influence. This area was, however, outside of the participants' control and while it influenced the way in which the adolescents managed their lives it was separate to the basic social-psychological process. Typologies of Support were outside the control of the adolescents because it is social environment (family, school and peers group of friends) that determines how an individual is viewed and treated. The adolescents could try to accommodate the wishes of their social environment and reconstruct themselves to meet social mores, values and expectations but they could not temper social perceptions towards themselves. Typologies of Support thus influenced how the adolescents managed their lives as they moved through the levels of process to Reach for the Light in that the level of outside support experienced by an individual determined whether they were able to cope with socially directed hostility. Those adolescents with Optimal Support were able to overcome social censure and Reach for the Light more ably than those with Minimal Support.

CHAPTER EIGHT

Closing Chapter

Introduction

The disorder AD/HD is one of the most commonly diagnosed childhood disorders in WA today, with controversy raging over its diagnosis and the best treatment. In the last decade AD/HD has emerged as a subject of serious debate in both academic and popular discourses. Adults such as parents, doctors and teachers, however, generally inform research so that the adolescent voice is rarely heard. This dissertation as a qualitative grounded theory study with a small group of adolescents with AD/HD from WA has set out to redress this lack of adolescent voice. Chapter eight intends to first review the criteria for judging qualitative research and grounded theory. Second, it presents a research summary and discusses the research outcomes and primary concerns that emerged from the data analysis. The chapter culminates with a discussion on areas for future research and the final statement.

Review of Qualitative and Grounded Theory Criteria

Chapter four outlined the steps that my research was to follow. Step 10 of this list advised that I would review my interpretation of the data both from my own and the perspective of others to establish generalisability, reproducibility, precision, rigour and verification in line with Glaser (1998) and Strauss and Corbin's (1990) rationale for grounded theory study and Piantanida and Garmen's

(1999) criteria for evaluating qualitative research. Although the reader is the one to judge this dissertation, as researcher it behoves me to ensure that the criteria are met. It is, therefore, my intention to briefly review my dissertation in light of the criteria for qualitative research in the grounded theory tradition discussed in chapters three and four.

Piantanida and Garman (1999) set out the following criteria by which to judge a qualitative study, they are: does the study have integrity, verité, rigor, utility, vitality, aesthetics and ethics. These criteria will now be discussed in the context of my research.

Integrity: I have endeavoured to present a study that is rational, logical and appropriate and firmly located within the inquiry tradition of grounded theory underpinned by the interpretative paradigm and symbolic interactionism. I have also been mindful of presenting the adolescent voice in a culturally sensitive way.

Verité: By referring to literature and documents relating to AD/HD and social theories relating to the stage of life referred to as adolescence I have endeavoured to illustrate how my dissertation fits the current discourse. Where concepts or problem statements differ from those in the field they have been explained.

Rigor: A systematic in-depth data analysis was undertaken. Where applicable, reference was made to the actual words of the participants indicating how ideas and concepts emerged from the data.

Utility: As far as has been possible to ascertain this is the first grounded theory study undertaken with a group of adolescents with AD/HD in WA to ascertain their perceptions of how they manage their lives. Despite the previously stated limitations of my research it makes a small but relevant contribution to the discourse in the field of AD/HD and may now extend upon current research.

Vitality: I believe that this project has allowed me to achieve a sense of vibrancy and discovery. I enjoyed working with this group of young people and greatly appreciate their help.

Aesthetics: Undertaking this work has broadened my research experience and brought, I believe, a greater depth of understanding to the work I do with

young people in my capacity as a researcher and as a tutor in special education. The words of the adolescent participants certainly “touched my spirit”.

Ethics: ‘To do no harm’ has been the guiding thought throughout this research. I have always been careful to conceal the participants’ names, while presenting their thoughts. Where appropriate I have always endeavoured to acknowledge my own assumptions and how they differed from those of the participants.

Glaser (1998) and Strauss and Corbin (1990; 1998) identified the criteria for grounded theory as fit, work and relevance.

Fit: It is suggested that the pattern of process explained in the data analysis defines the concepts that emerged from the data. The use of the adolescents’ own words in the discussion chapter ensures that the way in which a concept evolved is made clear. Constant comparisons were made throughout the discussion of the data and the theory that emerged to ensure that the substantive theory had fit.

Work: The process of Reaching for the Light was on the one hand directed at overcoming the main problem experienced by those with AD/HD that of Being Treated Differently. The way in which *balancing* and *fortressing* were employed during the process denoted how the participants continually sought to resolve any problems they experienced. On the other hand, Reaching for the Light conceptualises the process employed by this group of adolescents to achieve their aims and goals (*potentialising*) in order to manage their lives and experience equitability and autonomy in their world.

Relevance: The adolescent participants expressed an interest in my research. In particular they indicated that becoming aware that they were not unique in their experiences assisted them to understand themselves, their disorder and their experience of their social environment.

On revisiting the criteria for judging this study I think I endeavoured at all times to meet with these criteria in an honest way and to present a study that is both meaningful and useful in its field. A summary of my research now follows.

Research Summary

The aim of my research was to discover how a small group of adolescents diagnosed with AD/HD in WA using stimulant medication manage their lives. The central research question directing my study was as follows:

What is the experience of adolescents in WA diagnosed with AD/HD with regards to their diagnosis and the use of medication in the context of their home, school and social environment; in what ways do they manage their lives?

First, I set out to explore the participants' perceptions of their diagnosis and stimulant medication usage and to discover how these impacted on their lives. I then sought to ascertain whether the adolescents' social experience relating to their diagnosis and stimulant medication influenced how they manage their lives. All the data for my research was collected through interviews with adolescents with AD/HD; not their parents, teachers or the medical profession. My research presents, therefore, the unique perceptions of the lives and the problems confronted by these adolescents through their own eyes.

Chapter two with its discussion on background literature served to establish the need for my research. As the background literature demonstrated, the adolescent viewpoint regarding diagnosis and stimulant medication has, for the most part, either not been taken into account or their opinions have been discounted (Hazell, 2002; Prosser, 2000; Slomkowski et al., 1995; Tracey & Gleeson, 1998). Moreover, parents of adolescents with AD/HD, according to Barkley (1998) and Robin (1998), demonstrated a reluctance to relinquish control to their adolescents, as the parents feared that an AD/HD adolescent's tendency toward risk-taking behaviour would bring significant problems to them and their family. At the same time, research into adolescent AD/HD has been mainly viewed through the eyes of parents, teachers and the medical profession, rather than the adolescent themselves. Chapter two also identified that the stage of life referred to as adolescence, like that of AD/HD research, was in general directed by and based on the adult worldview of adolescence rather than the adolescents' worldview. (Bergin et al., 2003; Jenks, 2001; A. B. Smith, Taylor, et al. 2000). The discourse

relating to AD/HD and adolescence today is thus mainly the prerogative of adults rather than the voice and perceptions of the adolescents themselves.

A qualitative grounded theory research approach was employed underpinned by the interpretative paradigm and symbolic interactionism. This approach allowed for discovery from the data of action, reaction and process of how adolescents diagnosed with AD/HD manage their lives. Data were gathered in three phases. First, as a series of face-to-face, open-ended individual interviews with each of the participants, this was followed by two focus groups undertaken with five of the participants. The final phase of my research was a face-to-face semi structured interview with the first seven participants as well as three additional participants; this last phase was aimed particularly at deliberative theoretical sampling, although to a certain extent theoretical sampling is an on going process throughout the data analysis. Theoretical sampling as a process is guided by the emergent theory and is the point where coding, collecting and analysing is refined. Theoretical sampling then further directs data collection in order to build upon the emerging theory, hence the inclusion in the later stages of the project of three further participants who joined with the original participants to extend and verify the data

I acknowledge that my research has its limitations in that it does not provide a universal, generalised or representative picture of the experiences of all adolescents with AD/HD. Moreover, several challenges were encountered in the initial stages of this study, not the least of which was locating willing participants. Adolescents are often reluctant to talk to adults about their lives and it is my experience that adolescents with AD/HD are even more hesitant, fearing the consequences of labelling. The design of my research also had to be changed in order to accommodate the reluctance of some of the adolescents to participate in focus group interviews. The outcomes (the substantive theory and problem statements) of my research do not, therefore, provide an all-encompassing montage of the perceptions of all adolescents with AD/HD as to how they manage their lives. Rather, my research outcomes represent probability statements about the relationship between concepts that were discovered in the data and account for much of the behaviour seen in the substantive area of enquiry which is: how a small group of male and female adolescents in WA who have been diagnosed with

AD/HD and who receive stimulant medication as treatment, manage their lives in light of their social experience.

The experiences with my own children and with other young people with whom I work, particularly those with AD/HD, were the driving forces behind my research. But this research came to mean much more, for I came to sincerely admire all the participants for their maturity and courage, their tenacity and determination to succeed in the face of the many problems they encountered. I came to understand many aspects about adolescents and adolescent concepts of which I was previously not aware. This knowledge allowed me to interpret data from the adolescent perspective rather than the adult viewpoint. For example, when adults deem medication non-compliance as rebelliousness the adolescents referred to it as testing. Furthermore, adults expect adolescents to transform into socially acceptable mature individuals responsible for their own lives. Yet as Barkley (1998), Robin (1998), A.B. Smith, Taylor, et al. (2000) and Tracey and Gleeson (1998) contended, adults often fail to allow adolescents to make their own decisions or be the pivot in the decision making process aimed at resolving their needs, problems and concerns. This was particularly so for adolescents with AD/HD as my research data has demonstrated. As Prosser (2000) in his discussion about schools suggested, students with AD/HD resented teachers assuming that they should be passive receptors of interventions. The students in Prosser's study, like the participants in this research, saw these attitudes as condescending and tended to resist them. If adolescents with AD/HD are to take responsibility for him/herself, manage their lives and function effectively in adulthood then they require the support of their family, school and friends. To achieve these outcomes the adolescents need to be viewed as social agents in their own right not as beings in transition to be constructed by adults. For adolescents with AD/HD, the role of their parents, teachers and friends who make up their immediate social environment is, therefore, required to be essentially a supporting one, not a controlling one. Those in the immediate social environment of adolescents with AD/HD need to be patient, positive, understanding and uncritical.

Research Outcomes and Primary Concerns

Research Outcomes

The principal discovery to emerge from my research was the substantive theory Reaching for the Light, which was the basic social-psychological process that adolescents diagnosed with AD/HD employed to manage their lives. In order to achieve their aims and goals and Reach for the Light the participants moved through four levels of process: *seeking solutions*, *transforming*, *scaffolding* and *potentialising*. These four processes were supported by two near core categories of process, *balancing* and *fortressing* whose role was to intercede when necessary in the levels of process when the adolescent experiences problems and conflicts that they consider prevent or divert them from achieving their aims and goals (*potentialising*). Where five of the participants were able to move forward in the process of Reaching for the Light and considered that they were achieving their aims and goals (*potentialising*), the other five were experiencing greater difficulty. All of the participants utilised the categories of *fortressing* and *balancing* to overcome problems and conflicts in their lives on a regular basis. Some of the participants, such as those with the most significant problems and conflicts to cope with in their world, had the need to resort to *fortressing* and *balancing* on a far more regular basis than their peers as the *scaffolding* (the supporting frameworks in the social environment discussed in Typologies of Support) for this group with greater problems and conflicts was inadequate. These participants appeared to be locked into the processes of *transforming*, *fortressing*, *balancing* and *scaffolding*, although they still endeavoured to Reach for the Light.

The most significant problem experienced was that of Being Treated Differently. My research revealed that individuals discerned the way they were Being Treated Differently in unique ways. For example, for two female participants with AD/HD this was regarded in terms of levels of in-school bullying and victimisation. Another male participant associated his diagnosis and stimulant medication usage and Being Treated Differently with the negative attitudes directed towards him by his parents and friends. A further group of three participants saw Being Treated Differently as society's negative reaction to their diagnosis and stimulant medication usage. In their view, society blamed them (and their parents) for the problems associated with their disorder (lack of focus, poor

concentration and poor organisational skills). Society then located the blame for their behaviours and actions within the individual with AD/HD and stigmatised or labelled them. Other participants saw Being Treated Differently in a more positive light, as since diagnosis they were supported in their home and school environments as well as by their peers/friends. In view of this support these participants achieved a better understanding of not only the difficulties related to their disorder but also why society viewed some of their behaviour as inappropriate. This knowledge permitted them to achieve their aims and goals and to Reach for the Light.

The entire group of participants in my research indicated that they realised that the symptoms of their disorder led to them being different from some of their peers. Without exception the participants failed to understand why when they received stimulant medication to overcome the symptoms of their disorder they were labelled by some members of society as 'druggies'. As the participants remarked those with diabetes, asthma, or even a headache did not receive the same treatment from society when they ingested medication, why then should this be the experience of those with AD/HD?

During the interviews the participants all sought to clarify aspects of their diagnosis. Each of the participants placed great emphasis on the name applied to their diagnosis. Those who did not demonstrate to any degree the symptom of hyperactivity particularly preferred that their diagnosis be known as ADD. They considered this differentiation to be real and meaningful as society, encouraged by the media depicts ADD and AD/HD in two markedly different ways. In the participants' view, AD/HD was presented in the media as the 'out of control' child who had to be 'drugged into submission', whereas, those with ADD were not regarded in the same light. The term ADD no longer appears in DSM IV (American Psychiatric Association, 2000) rather, those without hyperactivity are classified in a different way such as AD/HD-PI.

My research has discussed how society determines specific expectations relating to normatively appropriate behaviour. For the adolescent with AD/HD to manage their lives they had to first come to terms with and understand these social mores, values, expectations and conventions. The pattern of social thinking that emerged as the pattern that directed and determined behaviours appropriate to a

social group, was that of socialisation. Where an individual does not conform to the rules, mores, expectations and conventions of the social group the labelling process serves to identify their patterns of behaviour as deviant. In other words, behaviours are labelled deviant if they do not conform to socially determined patterns of normatively appropriate behaviour. Those labelled deviant are stigmatised and ostracised by society. These theories of socialisation, labelling and deviance have endured, despite being theories of long standing, as frameworks for social mores, values, expectations and conventions. My research, like that of Prosser (2000) found that struggling with issues of social labelling and stigmatisation is the experience of adolescents with AD/HD. The participants saw the assigning of labels as detrimental to them. As chapter six has already indicated, the adolescents all expressed concern about being labelled, hence their fear of others finding out. They accepted and articulated that they were “unique” but expressed the view that this was no reason for them not be treated normally. The social expectations relating to normatively appropriate behaviour generated by these social theories are reinforced by the media. Where behaviours that are seen as deviant, such as crime and AD/HD, are presented by the media in a manner that generates a culture of fear in the public arena, this in turn impacts negatively on those involved.

Although the adolescent participants appreciated that their diagnosis of AD/HD and the use of stimulant medication brought with it an air of public scepticism and disbelief they did not appear to regret that they and(or) their parents sought the diagnosis. The discussion chapter alluded to the participants’ view that their diagnosis served to legitimate the difficulties they had been experiencing. If an adolescent is diagnosed with AD/HD then in their opinion, neither they nor their parents are to be blamed for the adolescent failing to conform to societies mores, values, expectations and conventions. Rather, in the participants’ eyes, the doctor’s diagnosis should confirm society’s value system of ill health and regards them as ‘ill’ not deviant. This was not necessarily the participants experience, however, as RB suggested when he stated that society does not object to and label an individual “headache man” when they take a Panadol for a headache, whereas, ingesting stimulant medication for AD/HD was seen in a derogatory light “oh **you** [*emphasis added*] are AD/HD”. The participants regarded this phrase as disparaging because

in their experience society tended to view those diagnosed with AD/HD as stupid, uncontrollable and incapable.

Several of the participants indicated that they preferred their diagnosis to remain a secret citing a fear of labelling or ostracism. The transference of the problems associated with AD/HD in adolescence to the doctor according to medicalisation and sickness theories (discussed in chapters two and six) placed pressure on the doctor to 'make the adolescent well'. If the doctor was not able to 'cure' the adolescent with AD/HD then in society's view they retained the label of deviant (non-conformist). The problem remained with the adolescent who then entered a phase of secondary deviation and the labelling process was further reinforced, leading to further ostracism and stigmatisation by society. According to Swain et al. (1993), it was the fear of different, the unknown, that led to the stigmatisation of individuals perceived as non-normal. On several occasions during interviews the participants evinced the view that they were saddened by the social stigma associated with their diagnosis and the utilisation of stimulant medication that emanated from within their social environment. Though in the participants' opinion, the stigma did not detract from the need for medical intervention to assist them to overcome their problems; as they pointed out that the medication helped them to achieve their aims and goals and more importantly Reach for the Light.

Primary Concerns

Nine interrelated primary concerns (problem statements) emerged from the discussion relating to the substantive theory Reaching for the Light.

The first, concern to emerge in my research related to labelling. By *seeking solutions* the group of adolescent participants demonstrated that they were able to begin to address their problems and the symptoms they had been experiencing. As they trialled stimulant medication and began to appreciate its benefits for their powers of concentration and focus they also began to understand why those in their social environment (parents, teachers and friends) found them frustrating. As one participant later acknowledged, "without my medication I do not like me" (RA). The diagnosis and the medical legitimisation of the adolescents' symptoms did not, however, alter society's perception of them as deviant and society continued to label them as such.

The second and one of the most significant concerns to emerge in my research was that this group of adolescents by introducing the process of *transforming* demonstrated that they were able to come to terms with their disorder in a rational and logical way. They also developed an understanding about society's expectations and perceptions about their disorder. With this knowledge they comprehended the need to reconstruct themselves to meet social mores, values, expectations and conventions. The participants accepted, albeit reluctantly, that this *transformation* was necessary. They saw it as a symbolic need based on their understanding of the cultural mores and values of their world. In doing so they, therefore, accepted the socialisation process. The adolescent participants were of the view that their medication enabled them to focus and concentrate on what they are doing, to be what they wanted to be and to do what they wanted to do. The adolescents rationalised that by accepting stimulant medication treatment they would be able to achieve their aims and goals and manage their own lives. In other words, the participants saw their medication as means to an end. They did not take the decision to continue using stimulant medication lightly, however, particularly when they were aware of society's negative attitude towards their medication. Rather, they approached their decision making in a rationate way.

It emerged from the data that the participants' viewpoint differed from that of the adults in their lives. Previous research by Brown, Borden, Wynne, Spunt and Clingerman (1987), Greenhill, Halperin and Abikoff (1999) had indicated that the failure of adolescents to ingest medication was regarded as rebellion and seen as non-compliance. Although all of the adolescents were diagnosed with AD/HD and trialed stimulant medication (sometimes without their parents agreement) they did not necessarily consider that stimulant medication was appropriate or their only option. There were times when they chose to discontinue stimulant medication usage. In the opinion of the adolescents rather than practicing non-compliance and rebellion they were demonstrating their need to test the usefulness of their medication before they considered its on going usage. My participants explained that they had to test the efficacy of their medication and to come to terms with the negative and positive affects of this medication before choosing their own pathway. This statement highlights the need for adults to include the adolescent in the decision-making process and to encourage them to vocalise the issues, concerns and problems they have relating to their medication.

The third and fourth concerns to emerge from my research were firmly linked with the previous two statements. The third re-emphasises what Barkley (1998) Brown (2000), Jensen (2000) and others have indicated, that careful titration of the medication is as important for adolescents with AD/HD, as it is for younger individuals. The relevance of careful titration of medication for my research is that if an adolescent with AD/HD is to accept the need for medication to treat the symptoms of their disorder the positive affects must outweigh the negative ones. The participants in my research were very aware of the problems associated with AD/HD such as poor focus and a lack of organisation and the impact these had on their social and educational outcomes. They acknowledged, however, that without their medication to assist them overcome these problems they could not manage their lives. As Barkley (2002), Hazell (2002) Woodward (2000) and many others have detected, adolescents with AD/HD were prone to greater levels of risk-taking behaviour, with greater levels of driving irregularities, teenage pregnancy, etc. Research has demonstrated, however, that stimulant medication usage allows those with AD/HD to ameliorate these problems and improve their academic and social outcomes. Though, as Barkley (2001b) suggested improved academic achievement did not indicate increased academic wisdom, but rather enhanced work productivity, classroom conduct and peer interactions that may lead to improved academic grades and better social outcomes.

Fourth, my research notes that care must be taken to ensure that comorbid disorders, in particular internalising disorders such as Anxiety Disorder and Depression are recognised and treated as necessary. An enormous body of research indicates that AD/HD is a real disorder that persists into adolescent and adulthood in significant proportion of cases. Those with moderate to severe symptoms are far more likely than those without AD/HD to have poor academic outcomes and to drop out of school; to have few or no friends; to engage in antisocial behaviours and to have poor self-esteem. They are also considered to be at increased risk of developing other problems such as anxiety, mood disorder and to use tobacco or illicit drugs more than those without AD/HD. During the research process one participant was diagnosed with comorbid depression. This depression impacted on her ability to succeed and her feelings of self-worth. The relevance of feelings of self-worth and their relationship to positive outcomes both academically and

socially were given particular weight in my research in light of data that suggested that severely negative social experiences, such as bullying in school, might lead to attempted suicide. This revelation is especially significant given the relationship between low self-esteem and attempted suicide in chapters six and seven.

The fifth area of concern that emerged from the data analysis was that there appeared to be a relationship between levels of self-esteem and internalised disorders, such as anxiety and depression. This thinking was in line with the views of researchers such as Barkley (2001c), Zubrick, Silburn, Gurrin, Teoh, Shepherd, Carlton and Lawrence (1997); Slomkowski, Klein and Manuzza (1995); Sawyer, Whaites, et al. (2002) and others. My research demonstrates that how an adolescent with AD/HD views him/herself and their levels of self-esteem is directly linked to their social experience and determines their ability to Reach for the Light. According to Blumer's (1969), symbolic interactionist perspective, human beings act towards things on the basis of the meanings that they assign to them and that they continually attributed meaning to objects through symbols and that these meanings derived from social interaction with society. As Vygotsky (Ratner, 1991) intimated, historical, institutional and cultural settings were the social frameworks from which individual consciousness emerged. Vygotsky and Blumer's views were similar to those of Goffman (1990) who suggested that how an individual presented self in everyday life arose from the arena in which that individual found him or herself. An individual's perception of self and feelings of self-worth, however, were also determined by whether this individual self was credited or discredited by the observer of the action, i.e., the others in their lives. According to Cote and Schwartz (2002), this process of shaping self was that of identity formation or individualization. In my research the processes of identifying, developing and shaping self may be witnessed in the categories of *transforming* and *potentialising*. These categories conceptualise how the adolescent with AD/HD comes to terms with themselves, their diagnosis and stimulant medication usage, as well as society's worldview of them. Through this understanding the adolescent with AD/HD shapes their awareness of how to reconstruct themselves (to transform and metamorphosise) and to manage their lives as members of contemporary society. It is critical, therefore, for the adults (parents and teachers) who are involved with adolescents with AD/HD to be aware of this factor; particularly as research in Australia by Zubrick et al. (1997) identified the

relationship between feelings of self-worth and suicide and attempted suicide in this age group.

This brings me to the sixth concern. According to the adolescent participants having good *scaffolding* was of enormous importance in their lives, as it was with secure scaffolding that they felt able to cope with the world around them and the problems they experienced. *Scaffolding* is defined in the dictionary as "a structure erected by workmen... while building or repairing a house" (Delbridge et al., 2001, p. 1229). This dictionary definition exemplifies the adolescents' beliefs relating to their *scaffolding*. The adolescents saw their *scaffolding*, as the supporting framework surrounding them that came from their family, school and friends. The Typologies of Support and their link with the *scaffolding* that was so important to each adolescent is one of the most notable problem statements to emerge from the data. The issue is that without affective, non-confrontational support from their family, school and friends the adolescent with AD/HD is more likely to have poor social and educational outcomes. As chapter seven illustrated, there would appear to be a direct link between the Typology of Support experienced by an adolescent with AD/HD and their ability to achieve their aims and goals and Reach for the Light. On the one hand those participants whose level of support was, in their eyes, negative or confrontational tended to become depressed and to resort to risk-taking behaviour to overcome their problems, these risk-taking behaviours may include medication substitution or even attempted suicide. On the other hand those participants with a more positive experience of their social environment considered they could achieve their aims and goals and Reach for the Light.

It became clear from the data that without positive, patient, uncritical support from their social environment adolescents with AD/HD were less likely to be able to achieve the core category and final stage in the level of process, that of *potentialising*. To achieve this point in their lives the participants have moved through the stages of *seeking solutions and transforming* and have secured the *scaffolding, balancing and fortressing* (the near core categories) were only infrequently required as secure *scaffolding* is the critical aspect. Those with *optimal support* and some with *selective support* had achieved secure *scaffolding* and were, therefore, able to achieve their aims and goals and Reach for the Light. Those participants who continued to move backwards and forwards through the

first three levels of process and for whom *fortressing* and *balancing* were essential tools, will sought to Reach for the Light as they continued to try and manage their lives.

The seventh concern to emerge from the outcomes of my research re-emphasises the importance of the adolescent with AD/HD being involved with and included in decision-making processes relating to their lives. My research identified that cultural sensitivity, such as being aware of the needs, problems and concerns associated with being adolescent from the adolescent perspective, was significant when establishing interventions for adolescents. This need took on particular significance for those whose experience of their social environment tended to be somewhat negative. It was specifically noted how critical it was for the adolescent participants that they were allowed by those in their social environment (family and school) to contribute and make decisions in discussions relating to any interventions to be carried out on their behalf, for instance, stimulant medication usage, or setting rules. My research concludes that without the involvement of the adolescent in the decision-making process strategies aimed at improving their social and academic outcomes were less likely to work. This notion is not new as it was previously identified as being of consequence by Barkley (1998), Robin (1998), Prosser (1998) and Tracey and Gleeson (1998) in their research. Rather, the conclusion that social and academic outcomes are more likely to be of value with adolescent involvement in intervention strategies reinforces the findings of previous research.

An eighth area of concern to emerge from my research, which is closely related to the other points raised so far, is that of the media and its influence on society. It was Furedi's (1997) contention that victimhood, as depicted by labelling and the media driven moral panic (discussed in chapter six) associated with a disorder such as AD/HD results in an individual's powerlessness and alienation. The adolescents in my research argued that they did not want to be the victims, to be labelled and ostracised and to be treated differently. They, therefore, endeavoured through the levels of process Reaching for the Light to conform to social expectations and to transform themselves to meet these expectations. The participants considered that the media often confounded their efforts. A sentiment also expressed by the participants in Prosser's (2002) study. Media driven moral panic and the culture of fear that appears to be promoted by the media towards

those with AD/HD tends to colour the perceptions of society towards those with the disorder and to influence the way in which they are treated by society, hence the stigmatisation and labelling that was the experience of these adolescents. It is my contention that where media driven moral panic occurs it is extremely damaging to those with AD/HD and their families. This view reaffirms and extends the thoughts of many eminent scholars, including those who contributed to the Consensus Statement (Barkley, Cook, et al., 2002). According to those who contributed to the Consensus Statement the media was and is, to an extent, responsible for the rhetoric surrounding AD/HD and for shaping society's view.

It is my contention that the adolescent participants demonstrated their maturity when they sought to overcome problems such as those associated with the media by employing the near core categories *fortressing* and *balancing*. The way in which they integrated these categories into their lives and into the levels of process in order to achieve their aims and goals and to manage their lives was remarkable.

The ninth and final concern, to emerge from my research was that there was a greater need for community awareness and acceptance of AD/HD as a disorder and of stimulant medication usage as treatment for the disorder. This concern draws attention to the frequently expressed opinions in the AD/HD literature in America, the United Kingdom and Australia, for example: Barkley (2001b), Barkley, Cook, et al. (2002), Hazell (2002), Hutchins (2002), Prosser (1997; 1998; 2000), Robin (1998) and Cooper and Shea (1998). My study further emphasises the findings of Cooper and Shea (1998) and Prosser (2002) that young people with AD/HD consider that the disorder impacted on them not only physically but also socially. The adolescents in my study also indicated that distinguishing between AD/HD and ADD was important to them. A view consistent with that of the participants in Cooper and Shea's study. The findings of my research confirm those of Cooper and Shea (1998) and Prosser (2002) that the adolescents saw diagnosis and treatment as legitimisation of their problems and a means of support. Although, unlike the students in Prosser's (2002) study who considered that it impacted only on their school environment, the adolescents in my study saw AD/HD as pervading all aspects of their lives. It is my contention that my study also reaffirms Hazell's (1997) view that it is important to distinguish

'adolescentness' from madness. Although parents and teachers perceive adolescents as difficult and disruptive, particularly those with AD/HD, in many instances the adolescents are only seeking to validate their knowledge base (such as testing the medication) and achieve their aims and goals. I acknowledge in my research that a remarkable quantity of work has been accomplished in the area of AD/HD to educate teachers, parents and society about the disorder. Despite this large body of work, as my data analysis indicated, there are those in society (adults and young people) who still present a negative critical attitude towards those with AD/HD, which serves not only to stigmatise those with AD/HD but to lead to that individual having poor feelings of self-worth that may result in depression and possibly attempted suicide. The adolescent with AD/HD needs the positive support and assistance of their parents, teachers, friends and society not their condemnation or criticism. A finding consistent with the view of Sawyer et al. (2002) who were of the opinion that children with mental disorders require support in many areas of their lives.

These primary concerns that emerged from my research are a series of interrelated statements that serve to demonstrate the enormous complexities that beset adolescents coping with the disorder AD/HD and the issues, concerns and problems that surround it.

Areas for Future Research

My research has presented the perspective of adolescents with AD/HD and their thinking in a way that is somewhat at variance to the current accepted discourse. The adolescent participants in my study believed that with the support of their family, school and friends they were able to manage their own lives. Even with less than adequate support they still wished to take charge of his or her own life. Current thinking, directed particularly by adults, does not come from the same viewpoint. Rather, the adult position is that they must continue to 'hold on to the reins' as adolescents with AD/HD are not capable of making their own decisions. My research with its small sample of participants in a specific location is somewhat limited. In order to extend and build upon this knowledge further study is required with adolescents both male and female with AD/HD as to how they manage their lives. The knowledge gained from my research with adolescents with

AD/HD coupled with a further body of knowledge may better assist parents and teachers to understand more where the adolescent with AD/HD is coming from, to involve the adolescents in the decision making process and 'to let go of the reins'.

The data in my research indicates that there is a need for further research related to low self-esteem in adolescents with AD/HD and its link with depression and attempted suicide. Although there is a wealth of material related to suicide with research currently in progress in the field of adolescent suicide I was unable to locate any literature specific to suicide or attempted suicide in adolescents with AD/HD. Two specific areas are, therefore, suggested for consideration; first, a study specifically aimed at discovering whether levels of suicide and attempted suicide by adolescents is higher in those with AD/HD than those without AD/HD and whether gender differences apparent in general adolescent suicide levels endure in those with AD/HD. Second, as low self-esteem is prevalent in adolescents with AD/HD it may be beneficial to parents, teachers and the medical profession for a study to be undertaken that seeks to discover whether there is a relationship between the level of social support experienced and attempted suicide. The aim of this research would be to discover whether lower levels of social support were instrumental in, or contributed to, an adolescent's poor self-esteem and by extension to their desire to take their own life.

Although an enormous amount of work has been undertaken to inform the public about AD/HD and the need for support for families and those with the disorder, both the families and those with AD/HD still experience very negative social attitudes. My research suggests that the media (particularly newspapers and television) plays a considerable part in developing this climate of fear associated with AD/HD. It is my contention that there is a need for the media to present to the public a balanced perspective that may assist the public to develop a culture of support for those with AD/HD and their families. A balanced view can only occur if the media itself develops an equitable attitude towards those who have the disorder and their families. It may, therefore, be appropriate for research to be undertaken into how the media can be encouraged to present a balanced view relating to the disorder so that a culture of acceptance may occur for those with AD/HD and for stimulant medication usage as treatment.

The Final Statement

The substantive theory Reaching for the Light is comprised of a series of interrelated social processes as adolescents pass through different stages in their lives. This basic social-psychological process discovered in my research was the one employed by a small group of adolescents with AD/HD in WA to manage a specific period in their lives. The significance of my research is that it presents the unique perceptions of a small group of male and female adolescents with AD/HD relating to how they manage their lives by coping with the issues and problems they encounter in their lives. By employing the grounded theory method I have endeavoured to present the voice of the adolescent. In doing so, my research builds upon existing AD/HD work and provides a forum from which further study can emerge. At the same time, my research seeks to overcome the apparent dearth of research relating to the personal experience of adolescents with AD/HD and in doing so contribute to the existing body of literature.

Closely associated with the substantive theory were the four different Typologies of Support that were the experience of the adolescent participants, Optimal Support, Selective Support, Concessional Support and Minimal Support. For the adolescents to manage their own lives required more than their own courage and the determination to reconstruct him or herself to meet social mores, values, expectations and conventions. They need the positive, patient, uncritical support of their social environment. The adolescents with Optimal Support levels were able to manage and forge new paths for themselves. For those of the participants whose support was less than wholehearted, managing their life became an uphill struggle against problems that they were determined to conquer. For all the participants, however, the ultimate goal was to Reach for the Light.

The foregoing analysis is primarily descriptive in order to clearly present the story to the reader. This study has sought to examine, describe and map out the influences on a small group of adolescents as they manage their lives. While the study does not have within its aims or objective the sort of detailed macro social influences that would enable greater explanatory power, it does provide substantial detail on a limited cohort. It is my belief that this method serves to demonstrate how the substantive theory was discovered. The concepts, which I have employed emerged from the data and were designed to fit the situation herein described.

Reaching for the Light as a process of reconstructing (*transforming* and *metamorphosising*) and *potentialising* self that was evident in this situation relates to individual social conformity to achieve social equilibrium. More generally, in line with social mores, values, expectations and conventions a person alters aspects of and reconstitutes their self in deliberate interaction with the changing pressures of life to achieve social equality. It is not only that people must socially reconstruct themselves but that their family, school and peers must also accept this new self and systematically build lines of patient, positive, uncritical support to interrelate with the metamorphosising person's new self. The general process of managing one's life by reconstructing self in face of problems to achieve social equilibrium e.g., managing a chronic condition, starting a new school or job, can be analysed, with appropriate variations, by the model discovered in my research.

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Appendix A

Doctor Request Letter



EDITH COWAN
UNIVERSITY

PERTH WESTERN AUSTRALIA

2, Bradford Street
Mount Lawley
Western Australia
6050.

Tel: [REDACTED]

e-mail [REDACTED]

June 2001

Dear Dr.

I am writing to request your assistance in locating adolescents - both male and female - to take part in a longitudinal research project to be conducted by me at The School of Education, Edith Cowan University. This study will first, seek to uncover the experiences and opinions, needs and problems of adolescents diagnosed Attention-Deficit/Hyperactivity Disorder (AD/HD) according to two subtypes, *ADHD Combined Type* and *AD/HD Predominantly inattentive Type* (with no comorbidities), with respect to their diagnosis and stimulant medication usage. Second the study will use grounded theory to construct theory about how adolescents with AD/HD manage their disorder and treatment strategies with the aid of youth driven individual case conferences.

The adolescents' participation will be invaluable in providing data necessary for this research. Identifying the experiences, opinions, needs and problems of adolescents with AD/HD and then using this material to develop youth driven case conferences that meet their needs and problems will, it is hoped, lead first to their self-esteem being enhanced and then to improvements in their social and educational outcomes. The benefits of the research will be significant for the children their parents, doctors and educators.

The research will involve the adolescents participating in a short interview to be conducted (if convenient) at your rooms immediately after diagnosis of Attention-Deficit/Hyperactivity Disorder (with no comorbidities). This will be followed by another interview a few days after the completion of any stimulant medication trial.

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A further interview will be conducted one month after these interviews. The first interview is expected to take 30 minutes and subsequent interviews approximately 30-60 minutes. These interviews will be followed by a focus group with all the adolescents participating in the study. Four adolescents, one from each gender and subtype will then be asked to undertake a short series of discussions - using the data from the initial interviews and focus groups - with the aim of developing youth driven individual case conferences (where the adolescent is their own advocate) thus allowing them their own voice in the management of the disorder and treatment strategies. The youth driven individual case conference model designed with the aid of the four adolescents will then, with your permission as well as that of the adolescent and their parents, be tested in the case conference scenario. A final focus group with all participating adolescents will evaluate the usefulness and effectiveness of the youth driven individual case conference model.

All interviews, discussions and focus group meetings will be conducted at a time and place suitable to the adolescent and their parent/guardian. With the permission of the adolescent and their parent/guardian the interviews will be tape-recorded and the focus groups video recorded. However, video recording of the focus groups will only take place if all participants agree to it. Given the length of the research project (approximately one year) I will (with permission) maintain contact through telephone calls or e-mails to the adolescents at home to discuss any further relevant experiences and opinions, needs and problems.

With your agreement and the parents' consent I will need to make contact with parents and their daughter or son prior to their first consultation with you to set up a time and place for the first and second interviews (These interviews will only take place if the adolescent in question is diagnosed AD/HD with no comorbidities). Would it be possible for you to identify possible suitable participants and request theirs and their parents permission to supply me with their names and addresses? On receipt of the necessary information I will then make contact with these parents and their daughter or son. They will receive the following letter, information sheet and consent form for completion. Parents/guardians willing to allow their daughter or son to take part will be asked to complete this consent form with their daughter or son.

Parents/guardians are free to decline their daughter or son's participation and neither they nor their daughter or son will be included. Should any adolescent decide to withdraw from the study, he/she may do so at any time without prejudice. No information relating to individuals will be supplied to any authorities or to anyone else. The experiences and opinions, needs and problems defined by the adolescents will be entirely confidential and imparted to no one unless they specifically request it. No identifying names will be used in any reports written about the study.

I really appreciate your assistance with this research and can assure you that I will continue in my efforts to understand and address the conditions which impact on children at home, school and socially.

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If you have any questions that you would like to raise about the study please contact Glenda Campbell-Evans, or myself we will be pleased to answer them. You can contact me on [REDACTED] and Glenda on [REDACTED] Your assistance in locating possible participants is greatly appreciated.

Yours sincerely

Mrs. Georgia Carragher Associate Professor Glenda Campbell-Evans
PhD Doctoral Research Candidate

Appendix B

Parent and Participant Consent Letter



EDITH COWAN
UNIVERSITY

PERTH WESTERN AUSTRALIA

2, Bradford Street
Mount Lawley
Western Australia
6050.

June 2001

Dear Parent/Guardian,

My name is Georgia Carragher and I am a PhD candidate at the School of Education, Edith Cowan University. I am currently conducting research into the experiences and opinions, needs and problems of adolescent's recently diagnosed Attention Deficit Disorder (AD/HD) and how they manage their disorder and treatment strategies. I understand from your paediatrician, Dr. [REDACTED] that you and your daughter or son has expressed a willingness to participate in the research. I now enclose further details of the research, an information sheet and consent form for you to complete and return to me in the enclosed stamped, addressed envelope.

My involvement with AD/HD has been as a parent and as a researcher dedicated to assisting those with AD/HD. I have been involved in research projects with children with AD/HD, their parents and school teachers for a considerable length of time. This present research project will first, seek to uncover the experiences, opinions, needs and problems of adolescent boys and girls with respect to their diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) and stimulant medication usage. (An information sheet is attached). Second to develop youth driven individual case conferences to assist the adolescent with AD/HD to better manage the symptoms of their disorder and the treatment strategies.

Your daughter or son's participation will be invaluable in providing data necessary for this research. Identifying their experiences, opinions, needs and problems associated with their diagnosis of AD/HD and the need to take stimulant medication and then (with yours and your daughter or son's permission) developing individual case conferences that meet their needs and problems will, it is hoped, help them to regain their self-esteem and be better able to manage their disorder and treatment strategies. The benefits of the research will be significant for your daughter or son, yourselves, doctors and teachers.

The research will involve your daughter or son participating in a series of interviews and focus group sessions. The first short interview will take place at your paediatrician's rooms, if convenient, or a nearby venue suitable to yourselves immediately upon receipt of a diagnosis of Attention-Deficit/Hyperactivity Disorder. (If your daughter or son is not diagnosed AD/HD they will not be asked to participate in the study). This first interview will be followed by another interview a few days later after any initial treatment. A further interview will be conducted one month after the first two interviews. These interviews will be followed by a focus group involving all the adolescents participating in the study. These interviews and the focus group will be arranged at a time and place suitable to yourself and your daughter or son. The first interview is expected to take 30 minutes and the subsequent interviews approximately 30 minutes to one hour. The focus group is expected to take approximately one to two hours.

The interviews will be tape recorded, with the permission of you and your daughter or son, to assist me to keep an accurate account of the experiences, opinions, needs and problems identified by the adolescents. False names will be used to identify participants. The focus groups will be video recorded to assist me to keep a clear record of what adolescents say in the group discussions. Video recording and/or tape recording of the focus groups will only occur if all those present agree to this. Once again false names will be used to identify participants and ensure confidentiality.

After I have collated and reviewed the information from these interviews the adolescents will then be asked to assist in developing a youth driven individual case conference model. The aim of these youth driven individual case conferences is to allow each adolescent to develop (with the aid of their parents, the paediatrician, the school and other health professionals) self-managed individual programmes that meet their specific needs and problems. The youth driven individual case conference model designed by the adolescents' will, with yours and your daughter or son's permission and with the permission of your paediatrician, be individually tested. It is proposed that this tried and tested model will then form the benchmark for developing youth driven individual case conferences for other adolescents diagnosed AD/HD. A final focus group with all participating adolescents will evaluate the usefulness and effectiveness of the youth driven individual case conference model.

Given the length of the research project, with yours and your daughter or son's permission, I will maintain contact through telephone calls or e-mails to your daughter or son at home so as to discuss any further thoughts and experiences they may have.

No information relating to any individual or their family will be supplied to any authorities or to anyone else. The thoughts and experiences of the participating adolescents will be entirely confidential and imparted to no one unless they specifically request it. No names will be used in any reports written about the study.

If you and your daughter or son are willing for them to take part, please complete the attached form and return it in the envelope provided. If you or they would rather not take part you are free to decline, you and your daughter or son will not be included. Should your daughter or son decide to withdraw from the study, he or she may do so at any time without prejudice.

I greatly appreciate yours and your daughter or son's assistance with the research and can assure you that I will continue in my efforts to understand and address the conditions that impact on children at home, school and socially.

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If you have any questions that you would like to raise with me about the study I, or my supervisor Associate Professor Glenda Campbell-Evans, will be pleased to answer them. You can contact me on [REDACTED] and Glenda on [REDACTED]

Yours and your daughter or son's co-operation is very much appreciated.

Yours sincerely

Mrs. Georgia Carragher
PhD Doctoral Research Candidate

Glenda Campbell-Evans
Associate Professor

Appendix C

Information Sheet and Consent Form



EDITH COWAN
UNIVERSITY

PERTH WESTERN AUSTRALIA

2, Bradford Street
Mount Lawley
Western Australia
6050.

Tel: [REDACTED]
e-mail [REDACTED]

RESEARCH INFORMATION SHEET

Recent research has identified that adolescents diagnosed with Attention-Deficit/Hyperactivity Disorder (AD/HD) have low self-esteem and are at risk of poor social and educational outcomes. However, this research has failed to identify the experiences, and opinions, needs and problems of adolescent boys and girls diagnosed by each of two subtypes, *AD/HD Combined Type* and *ADHD Predominantly inattentive Type*, (with no comorbidities) with regards a diagnosis of AD/HD and stimulant medication usage. By discovering and listening to their experiences and opinions, needs and problems related to AD/HD and stimulant medication use a new initiative - youth driven individual case conferences - is to be developed to assist adolescents with AD/HD to manage the symptoms of their disorder and the treatment strategies. We, at Edith Cowan University, need the help of your daughter or son to assist us in developing this new initiative for adolescents.

So what do we request of you and your daughter or son? Briefly, that after initial diagnosis of AD/HD (with no comorbidities) by a paediatrician your adolescent takes part first, in three short interviews, then a focus group, followed by a short series of discussions and a final focus group, all over a period of approximately 12 months. The researcher would also like to talk with your daughter or son by telephone or e-mail between interviews and discussions. The interviews, focus groups and discussions will be at a venue of yours and your adolescent's choice. With the permission of you and your daughter or son the interviews will be tape-recorded and the focus groups video recorded and or tape recorded. For the focus group to be video recorded and(or) taped recorded all the participants must agree. All the information imparted at the interviews and in the telephone conversations or e-mails by the adolescent will remain confidential. We will only pass on information at the specific request of the participating adolescent.

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Parents and adolescents will receive a full copy of the research and an invitation to attend a seminar where all findings will be explained and questions answered. If you have any questions please ring Georgia Carragher on [REDACTED] or Associate Professor Glenda Campbell-Evans on [REDACTED]

PERMISSION TO PARTICIPATE IN A RESEARCH PROJECT



**EDITH COWAN
UNIVERSITY**

PERTH WESTERN AUSTRALIA

2, Bradford Street
Mount Lawley
Western Australia
6050.

Tel: [REDACTED]
e-mail [REDACTED]

CONSENT FORM

Project Title: The voice of the adolescent with Attention-Deficit/Hyperactivity Disorder (ADHD) in individual case conferences: How adolescents with AD/HD manage the symptoms of their disorder and the treatment strategies.

I give permission for my adolescent
.....to participate in the research project conducted by
Georgia Carragher, PhD candidate, Edith Cowan University.

I have read the letter and information sheet about the above research project explaining the purpose of the project. I understand that my daughter or son's participation may involve a number of interviews, discussions and focus groups over a period of one year. Any questions I have asked have been answered to my satisfaction.

I understand that I am free to decline, and that my daughter or son is free to decline to participate; furthermore, my daughter or son may withdraw from the study at any time without prejudice.

I understand that I can call on Georgia Carragher on [REDACTED] or her PhD supervisor, Associate Professor Glenda Campbell-Evans on [REDACTED] and request additional information about the study.

I understand that no names will be used in any results or publications arising from the study, and that all information collected will be treated in strict confidence. All tape recorded or video recorded material will be held in a secure filing cabinet in room 16.224. This room can only be accessed through the security code pad on the door.

I agree that the research data gathered for this study may be published provided that neither my daughter or son nor I are identifiable.

signed Date
(Parent/Guardian's signature)

Participant's signatureContact phone number

Appendix D

Formal Interview Questions

Interview Questions	Phase One Three individual Interviews	Phase Two Focus Groups	Phase Three Semi-structured face-to-face interviews for discriminating theoretical sampling
In what way do adolescents with AD/HD (both male and female) perceive their diagnosis and stimulant medication usage?	√	√	√
To what extent do a diagnosis of AD/HD and the subsequent use of stimulant medication impact on an adolescent at home, in school or socially?	√	√	√
In what ways do adolescents with AD/HD consider their diagnosis and the use of stimulant medication engenders the needs and problems they experience at home, in school, or socially?	√	√	√
What do the adolescents with AD/HD consider they are good at? What are their strengths?	√	√	
What do the adolescents like to do?	√	√	
How and to what extent have these perceptions changed during the study?	√	√	√
What, in the opinion of the adolescents' are the most significant needs and problems identified in phases one and two?			√
To what extent does identifying these needs and problems help them to manage their lives better?			√
What strengths were identified in phases one and two?			√
To what extent will identifying their strengths assist them in managing their lives?			√
In what way do they consider their treatment should be managed?			√

-2-

Interview questions contd.

Interview Questions	Phase One Three individual Interviews	Phase Two Focus Groups	Phase Three Semi-structured face-to-face interviews for discriminating theoretical sampling
In what way do they manage their social experience?	√	√	√
If support is deemed necessary will it assist them to better manage the problems they have identified associated with their disorder?	√	√	√
Whom do they consider is best suited to help them manage their lives and overcome the problems they experience?	√	√	√
To what extent do adolescents with AD/HD consider their self-esteem will improve if they have self-management of the problems associated with their disorder and treatment regimes?	√	√	√
Overarching question - How do adolescents with AD/HD (male and female) manage their lives in light of their social experience.	√	√	√